PERSON FIRST:

AN INVESTIGATION AND LEGAL ANALYSIS

of People with Intellectual and Developmental Disabilities in New Jersey Nursing Homes

DISABILITY RIGHTS NEW JERSEY

ADVANCING JUSTICE. ADVOCATING INCLUSION.

The New Jersey Council on Developmental Disabilities

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OCTOBER 2023

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ABOUT THIS REPORT

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Disability Rights New Jersey is deeply appreciative to the New Jersey Council on Developmental Disabilities, whose vision and financial support made this report possible. In addition to financial support, the Council offered its wisdom, access to stakeholders and families, and unwavering support for advocating to move New Jersey toward a truly just, inclusive, and person-centered delivery system of services and supports for people with intellectual and developmental disabilities and their families.

We also posthumously thank **Beverly Roberts** of The Arc of New Jersey and member of the Medical Assistance Advisory Council (MAAC), who early in our efforts pressed the state Medicaid agency, as only she could, to answer hard questions about people with IDD in nursing homes and, in doing so, helped launch this effort. Disability Rights New Jersey dedicates this report to her memory.

This report was revised on May 10, 2024 to address ambiguities and updates in the presentation and interpretation of federal data. For more information, see pg. 24, endnote 68.

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LETTER TO THE COMMISSIONERS OF HUMAN SERVICES AND HEALTH

October 2, 2023

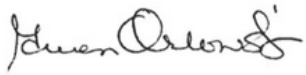
Dear Commissioner Adelman and Acting Commissioner Baston:

On behalf of Disability Rights New Jersey, the designated Protection and Advocacy system under federal law, we are pleased to share our report about the current state of individuals with intellectual and developmental disabilities (IDD) in New Jersey nursing homes. From April 2022 through August 2023, Disability Rights NJ visited 70 nursing homes throughout New Jersey and met with hundreds of individuals with IDD living in those nursing homes. We spoke with dozens of guardians and key stakeholders. We also closely analyzed our findings through the lens of the Americans with Disabilities Act, *Olmstead v. L.C.*, and federal and state laws around, principally, the federal law governing Preadmission Screening and Resident Reviews (PASRR), the federal Home and Community-Based Services Settings rule, including the significant person-centered planning rights components of that rule, and the federal rights afforded to nursing home residents.

This report investigates and analyzes whether nursing homes have replaced Developmental Centers as the default institutional setting for people with IDD, and whether the State is using all available federal laws including PASRR and the person-centered planning rights in the federal HCBS Settings Rule to develop and execute a comprehensive, effective *Olmstead* plan. We also looked closely at whether people with IDD who need the services of a nursing home and chose to live in that institutional setting are receiving the specialized services they are entitled to receive.

Our findings and recommendations are discussed in detail in this report. We know from our conversation with the Department of Human Services that efforts are already underway to correct the most serious violations of the federal PASRR requirements, and we look forward to discussing those efforts and our recommendations soon. We would also like to express our gratitude to all those in the Department of Human Services, and in particular Assistant Commissioner Jennifer Langer Jacobs and Assistant Commissioner Jonathan Seifried, who graciously gave us their time, aiding in our efforts to collect important information and understand current systems.

Very truly yours,



Gwen Orlowski
Executive Director
Disability Rights New Jersey

INTRODUCTION & EXECUTIVE SUMMARY

INTRODUCTION

In March 2020, the COVID-19 pandemic hit New Jersey's nursing homes fast and hard, and since then nearly ten thousand nursing home residents have died of the virus.[1] Among those in nursing homes who died or suffered from COVID-19 were far too many people with intellectual and developmental disabilities (IDD)[2] – people who arguably should not have been there in the first place.

Even before the pandemic, Disability Rights NJ began questioning the presence of people with IDD in nursing homes, asking: How many people with IDD are living in nursing homes? Who are they? Why are they residing in nursing homes rather than their own homes or in home and community-based settings (HCBS)? Where exactly are they living – which nursing homes? While the State's Medicaid agency began to provide limited information in 2019, that information raised more questions than it answered; before advocates could get clarity, COVID-19 struck.

The basis of our concern and inquiry, both before – and with a sense of heightened urgency – after COVID-19 began is rooted in the United States Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), which held that the unjustified segregation and isolation of people with disabilities, particularly in institutions, by the state is discrimination in violation of Title II of the Americans with Disabilities Act (ADA).[3] The Supreme Court further held that states must provide services and supports to people with disabilities in the most integrated setting appropriate to meet the needs of the individual, recognizing that those settings must enable people with disabilities "to interact with non-disabled persons to the fullest extent possible."[4]

This emphasis, on ensuring that people with IDD live in the most integrated setting appropriate to their needs and desires, is also reflected in other federal laws designed to foster state compliance with *Olmstead* (e.g., the Preadmission Screening and Resident Review requirements or PASRR, the Home and Community-Based Services Settings Rule, Minimum Data Set or MDS PASRR reporting requirements, Section Q of the MDS, and various components of nursing home assessment and plan of care requirements).[5]

Disability Rights NJ has a deep history of fighting against New Jersey's over-reliance on institutions for people with disabilities, both in state-operated Developmental Centers for people with IDD and in state-operated psychiatric hospitals for people with mental health disabilities, including using our federal authority to secure the civil rights of people with disabilities living in those institutions through systemic litigation.[6]

In two lawsuits filed against the State of New Jersey in 2005 and 2008, Disability Rights NJ

challenged the State's practice of illegally segregating people with IDD into large state-run Developmental Centers and failing to provide sufficient community-based services and supports, including affordable, accessible housing.[7] The twin lawsuits alleged that the shortage of community services created both a backlog of residents stuck in institutions who wanted to live in the community, and of people living in family homes who needed residential services but were on a wait list almost indefinitely.

In March 2013, Disability Rights NJ finalized a settlement agreement covering both lawsuits that at the time, dramatically expanded the availability of community residential placements, diverted unnecessary institutional placements from Developmental Centers, and required the State to find community placements for all 600 eligible Developmental Center residents over a five-year settlement monitoring period. The State met and exceeded its obligations under the settlement agreement by the end of the monitoring period in 2018.[8]

In addition to the explicit *Olmstead* mandate to ensure that people with disabilities have meaningful choice to live in integrated community-based settings rather than Developmental Centers, Disability Rights NJ's advocacy efforts in the nursing home space has increased significantly since COVID-19.[9] Through our work in nursing homes, we have concluded that, for the most part, New Jersey's facilities evoke a hospital-like environment with traditional staffing models that are not conducive to a person-centered planning or delivery model for all residents, including people with IDD. And until the model is substantially redesigned, many nursing homes are dismal places for anyone to live.[10]

With this background – the apparent significant number of individuals with IDD in nursing homes, the clear *Olmstead* mandate, federal laws designed to foster the most integrated community-living appropriate to the needs and desires of the individual with IDD, and our work to depopulate the Developmental Centers – Disability Rights NJ was left asking: **Have nursing homes replaced Developmental Centers as the default institutional setting for people with IDD?**

In the face of inadequate home and community-based settings and services, is the State still isolating, segregating, and discriminating against people with IDD, albeit in a nursing home setting? Are state policies and processes failing to engage people with IDD in robust discussions about their choice of community-based options? And are people who need the services of a nursing home and choose to live there receiving services specific to their IDD diagnosis?

This paper focuses on Disability Rights NJ's systemic investigation to answer these questions through nursing home site visits, in-person interviews with nursing home residents with IDD, input from private guardians and the Bureau of Guardianship Services (BGS), interviews with State partners and other stakeholders, and a review of key resident documents.

EXECUTIVE SUMMARY

After our extensive investigation into allegations of neglect and rights-based violations (see infra at Investigations, p.12) related to people with IDD residing in nursing homes, Disability Rights NJ concluded that people with IDD end up in nursing homes, frequently without their consent or contrary to their expressed wishes because New Jersey's network of home and community-based settings, services, and supports are simply inadequate to meet the needs of all people with IDD, especially those with complex support needs. New Jersey lacks sufficient affordable, accessible housing overall, and specifically with respect to people with IDD. New Jersey has significant gaps in truly individualized, person-centered services and supports especially as needs change with age or otherwise increase in complexity or intensity. New Jersey's mechanisms to ensure that people with IDD can return to their homes after acute hospitalization or short-term nursing home rehabilitation are frequently ineffective and procedural protections from unlawful evictions from HCBS settings, like group homes, are minimal. All of these findings bespeak a grave *Olmstead* problem related to the over-institutionalization of people with IDD in nursing homes.

Given these overarching concerns, Disability Rights NJ identified three central problems:

1 **The State of New Jersey does not have an accurate count of the number of people with IDD living in nursing homes, nor does it have important information about those people.**

The State of New Jersey does not have an accurate count of the number of people with IDD residing in nursing homes and may well be undercounting that number by a factor of between 24% and 37% during the period reviewed. Given that the State does not have a complete list of people with IDD in nursing homes, it cannot effectively collect and maintain complete, consistent, and accurate data about these individuals. The data is critical, both to ensure the State is meeting its obligations under the U.S. Supreme Court's *Olmstead* decision, and to ensure the State has the data it needs to both plan for the future, including and advancing equity as it builds out its home and community-based housing, services, and supports.

It is also important that New Jersey provides demographic data about people with IDD in nursing homes, as well as aggregated PASRR data to the public in a transparent and understandable manner on a regular basis.

Disability Rights NJ found federal data that demonstrates that nearly 20% of the people with IDD who were in nursing homes in late 2019 and early 2020, just prior to COVID-19, were no longer there by June 2020. However, we do not have data explaining what happened to those individuals – did they leave and go to group homes or family homes? Did they die? Is there another explanation?

2 **The State of New Jersey's PASRR system is irrevocably broken in that it is out of compliance with federal law and not functioning in accordance with its federal *Olmstead* purpose to divert and transition people with IDD and mental health disabilities from nursing homes to less restrictive settings with needed services and supports.**

PASRR is a federal law that requires individualized and thorough screenings and evaluations of all people with IDD or mental health disabilities (MI) before being admitted to a nursing home as well as upon a change of condition for people already living in a nursing home. New Jersey's PASRR system is designed to circumvent individualized, person-centered requirements, by over-using mechanisms to avoid the full evaluation process – the system appears to encourage evaluators to rubber stamp pre-determined decisions to admit people with IDD and MI into nursing homes without meaningful exploration of HCBS alternatives and less restrictive settings appropriate to needs. The result is the over-institutionalization of people with IDD in nursing homes. In addition, because the State's definition of "specialized services" is at odds with the federal law, people who choose and need nursing home services are denied the specialized services for their disabilities they are entitled to receive.

3 **Throughout the State, people with IDD are not afforded their constitutionally protected right to self-determination regarding where they live, nor are they afforded meaningful opportunities to engage in federally mandated and assured person-centered practices. As a result, people with IDD are forced into nursing homes and are thus denied interactions with non-disabled people: a choice of one – a nursing home – is not a choice.**

Under the State constitution, people with IDD have the right of self-determination, including the right to express a preference about where they live. The New Jersey Supreme Court has ruled that the right to express a preference about where one lives continues in a general guardianship, absent a finding by clear and convincing evidence that a person with a disability lacks capacity to make that specific decision. Even then, the New Jersey Supreme Court ruled that guardians must "give as much weight as possible to the right of self-determination." This state constitutional right is amplified by the right to person-centered planning in both nursing homes and home and community-based settings under federal law. People in New Jersey with IDD confronted with a nursing home admission or long-term residency are regularly denied the full measure of their state constitutional and federal rights to self-determination, particularly in the choice of where to live, as well as control and autonomy of their plans of care in those settings.

HIGHLIGHTED RECOMMENDATIONS:

Along with these significant findings, Disability Rights NJ makes detailed recommendations, set forth infra, in Recommendations and Conclusions, p. 57.

All of Disability Rights NJ's recommendations are rooted in the need to radically change the State's home and community-based settings and services system to be truly individualized and person-centered. This requires a fundamental shift in thinking from a model rooted in paternalistic notions of safety to one rooted in the maximum recognition of and support for autonomy and self-determination for people with IDD, even those subject to guardianship. In order to achieve this and come into compliance with the ADA and *Olmstead* requirements, New Jersey must develop and implement a

comprehensive, effective working plan for nursing home diversion and transition to ensure people with IDD can live and be supported in home and community-based programs.

- New Jersey should develop a cross-agency, centralized data storage system that collects and maintains complete, consistent, and accurate data related to people with IDD (and mental health disabilities) living in nursing homes. This database should be used to inform the development of the State's nursing home *Olmstead* plan.

- New Jersey should collect and/or aggregate existing data related to demographic information (e.g., age, race, ethnicity, disability, language spoken, sexual orientation, or gender identity) that would aid in examining implicit bias in the long-term care services and supports delivery system, and assist state policy makers as they build out future opportunities to advance equity in home and community-based settings.

- New Jersey should maintain and publish a public dashboard that includes aggregate, non-personally identifiable information about individuals in nursing homes with disabilities including IDD and mental health disabilities.

- New Jersey should adopt and implement PASRR quality monitoring and quality improvement (QM/QI) indicators critical for measuring and promoting the success of the State's PASRR program using CMS's model list of QM/QI measures, as well as tracking individuals with disabilities at risk of or living in nursing homes.

- New Jersey should analyze MDS 3.0 data related to PASRR before and directly after COVID-19 hit the State's nursing homes in 2020 to determine if it is accurate that nearly 20% of the individuals with IDD were no longer living in nursing homes from March 2020 to June 2020.

- New Jersey should undertake a thoroughgoing review of the State's current PASRR process for people with both IDD and mental health disabilities in light of current federal requirements and technical assistance available through CMS, including the state's definition of "specialized services." This process must include key stakeholders, including people with IDD, their families and advocates.

- New Jersey should amend and/or adopt relevant statutes and regulations to design and implement a PASRR system that both complies with CPR regulations and is a powerful tool in the State's nursing home *Olmstead* plan.

- New Jersey should keep principles of person-centered thinking at the forefront of the redesign of the state's PASRR process, and, with deliberation and intention, incorporate person-centered processes into all aspects of the PASRR process.

- The state Medicaid agency should seek State Plan Amendments from CMS for specialized services, including waiver-like specialized services designed to promote continuity of care between HCBS settings and nursing homes with the goal of promoting nursing home diversion and transition.

- As part of the implementation of a new PASRR system, New Jersey should engage

in comprehensive outreach and training to all participants in the system and should call on the expertise of Disability Rights NJ as the designated Protection & Advocacy (P&A) system, the Boggs Center on Developmental Disabilities, the New Jersey Council on Developmental Disabilities, the Ombudsman for Individuals with IDD and Their Families, and the New Jersey Long-Term Care (LTC) Ombudsman as part of the outreach and training.

- New Jersey should review person-centered rights and practices throughout the Long-Term Services and Supports (LTSS) delivery system, including nursing home practices, Managed Long-Term Services and Supports (MLTSS), and the DDD-administered waivers, to ensure compliance with the constitutional right to self-determination, with federal law, and with pervasive person-centered thinking. Key stakeholders should be part of these discussions.

- In line with revisiting all person-centered practices, New Jersey should review and revise requirements for HCBS waiver written service plans and the planning process, consistent with HCBS rule, to ensure robust person-centered written service plans that are not defined exclusively by covered Medicaid services and include innovative ways to meet individuals' broader goals and desired outcomes.

- For people in nursing homes with IDD coming from DDD-administered waiver programs who intend to return to their home in the community, New Jersey should review practices related to moving people with IDD from the Supports or Community Care Program to MLTSS prematurely. At the very least, DDD clients should generally remain on DDD waivers for the full 180 days currently approved by CMS. DDD clients in nursing homes should maintain their pre-institutionalization Support Coordinator during this time, ideally for all 180 days, and Support Coordinators should have additional specialized training in nursing home diversion and transition.

- In addition to ensuring that New Jersey regulations include all the person-centered protections of the federal nursing home and HCBS regulations, New Jersey should review and amend all state regulations related to nursing homes to comply with the fullness of the 2016 federal Code of Federal Regulators (CFR) regulatory changes (e.g., protections from involuntary discharge and visitation).

- New Jersey should develop and implement an *Olmstead* "comprehensive, effectively working plan" for placing nursing home residents with disabilities, including IDD, in community-based programs. The plan should acknowledge the lack of affordable, accessible housing and appropriate, individualized services and supports in the State, and proactively plan to develop the housing and supports needed to meet the full demand for all people, including people with IDD living in or at risk of nursing home placement.

- As part of developing and maintaining affordable, accessible housing, New Jersey should revisit recently adopted regulations meant to comply with the settings portion of the federal 2014 Home and Community-Based Services Settings rule that went into effect in March 2023. Special attention should be paid to the failure of the newly adopted regulations

to provide HCBS tenants with protections consistent with New Jersey's Anti-Eviction Act.

- The Department of Health should hire sufficient Survey staff and provided in-depth training to Surveyors on PASRR, Residents Rights, and person-centered care planning to better identify and cite these violations. Survey staff should have a baseline understanding of the State's *Olmstead* plan for nursing home residents and have high functioning referral processes with other state agencies (e.g., LTC Ombudsman's I Choose Home program).

In addition, Disability Rights NJ offers our assistance as the designated Protection and Advocacy system for the State of New Jersey to the Department of Human Services as well as to the Department of Health to help implement the radical change that this moment, informed by a world-wide pandemic, demands. We also encourage the State to engage other invested and important stakeholders, including people with disabilities living in nursing homes or at risk of institutionalization and their families, into this important discussion.

THE INVESTIGATION

DISABILITY RIGHTS NJ'S SYSTEMIC INVESTIGATION

DISABILITY RIGHTS NJ'S AUTHORITY TO CONDUCT SYSTEMIC INVESTIGATIONS

As New Jersey's designated Protection and Advocacy system (P&A), Disability Rights NJ derives our authority to conduct investigations of incidents of abuse and neglect from a series of federal statutes, including the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), which, in part, requires states to have in effect a protection and advocacy system to protect the legal and human rights of individuals with intellectual and/or developmental disabilities (IDD).[11] Disability Rights NJ was designated this system for people with IDD in New Jersey by Governor Christie Todd Whitman in 1994.[12]

Under the DD Act, Disability Rights NJ has the authority to investigate incidents of abuse and neglect of people with IDD if the incident is reported to us or if we have probable cause (e.g., which can be the result of monitoring or other activities, including media reports and newspaper articles) to believe that abuse and neglect have occurred.[13] Incidents of abuse and neglect can focus on one individual, or many individuals similarly situated, especially in congregate settings like nursing homes. Examples of abuse and neglect include: at the discretion of the P&A, a violation of an individual's legal rights; any practice which is likely to cause immediate physical or psychological harm or result in long term harm if the practice continues; or failure to establish or carry out an appropriate individual service plan (including a discharge plan).

In addition, Disability Rights NJ also has broad authority to access resident records (generally with consent, but, under certain circumstances, without the consent of the person with the IDD or guardian, if there is one),[14] as well as reasonable unaccompanied access to individuals with IDD at all times and to service providers and their premises that are used by people with IDD.[15]

Even before the COVID-19 pandemic ravaged New Jersey nursing homes leading to the death of more than 4500 residents between March and May 2020,[16] Disability Rights NJ raised concerns about people with IDD living in nursing homes with the State of New Jersey's Department of Human Services (DHS): Division of Medical Assistance and Health Services (Medicaid agency) and Division of Developmental Disabilities (DDD). Through our individual investigation and monitoring work, we saw people with IDD living in nursing homes, though we did not know how many or why they were in these institutional settings. Through the lens of our mission to protect the legal and human rights of individuals with IDD, including rights under the *Olmstead* decision, Title II of ADA, and nursing-home specific laws like the Preadmission Screening and Resident Review (PASRR) requirements, we determined that we had probable cause to believe abuse and neglect, including rights-based violations, were occurring. Our concerns were echoed by other advocates, stakeholders, and families who were similarly concerned that there were a substantial, unknown number of people with IDD living in nursing homes.

In 2019, Disability Rights NJ, alongside other advocates, asked the Medicaid agency for basic information about the numbers of people with IDD living in nursing homes through the Medical Assistance Advisory Council (MAAC).[17] In response, the Medicaid agency provided data at two MAAC meetings in April 2019 and July 2019:

- At the April 25, 2019 MAAC meeting, the Medicaid agency provided data on the number of IDD recipients residing in a nursing facility between July 2014 and December 2018. For example, in December 2018, the Medicaid agency reported that there were 597 individuals with IDD living in nursing facilities.[18]

- At the July 25, 2019 MAAC meeting, the Medicaid agency again provided data on the number of IDD recipients residing in a nursing facility between July 2014 and December 2018, and made clear this data included both Medicaid Managed Long Term Services and Supports (MLTSS) and fee-for-service (FFS) Medicaid recipients. For example, in December 2018, the Medicaid agency reported that there were 611 individuals with IDD living in nursing homes, an increase of 14 residents over the data presented in April, seemingly due to the addition of FFS residents.[19]

In addition to the data presented at the MAAC meeting on July 25, 2019, MAAC members and public attendees shared ongoing concerns about people with IDD in nursing homes, reflecting that while the data provided was helpful, more information was needed including: what circumstances gave rise to them ending up in nursing homes; whether they were being referred to nursing homes by DDD or at the county level; and the appropriateness of the placement and access to services. Concerns were raised that people with IDD who were hospitalized and then had a nursing home stay could not go back to their previous living situation, whether a group home or their own home because there were inadequate and/or insufficient services in the community, or that the previous setting simply refused to allow the person to return.[20]

Before these and other questions could be answered, New Jersey was plunged into the darkest days of the COVID-19 pandemic, and it was quickly evident that the state's nursing home residents were particularly vulnerable as nursing homes were "hot spots for infectious disease outbreaks" and were soon overwhelmed by COVID-19.[21] Manatt Health completed a report on June 2, 2020 into the state's COVID-19 response in the long-term care (LTC) system and found, while COVID-19 did not create systemic problems in NJ's nursing homes, it did amplify existing problems including:

- A larger percentage of nursing homes had documented infection control deficiencies and citations going into the pandemic and were ill-equipped to provide effective infection control once COVID-19 hit the state in March 2020;

- Nursing homes experienced long-standing staffing shortages or low staffing ratios, and were staffed by workers who came, in many cases, from communities with large outbreaks of COVID-19 leading to significant community spread inside nursing homes; and

- There was no LTC-focused preparedness plan prior to COVID-19, leading to a lack

of personal protective equipment (PPE), inability to cohort residents (in part because so many nursing homes were old facilities and had 3 and 4 bedded rooms), staffing back up plans, or alternative means of communication, especially with families, once facilities shut down.[22]

Throughout March and April 2020, Disability Rights NJ worked tirelessly to address the many COVID-19 issues specific to people with disabilities (e.g., hospital visitation policies, rationing of healthcare resources, monitoring the state's Developmental Centers and psychiatric hospitals).[23] On April 15, 2020, our attention turned to a nursing home in North Jersey, Andover Subacute and Rehabilitation Center II (Andover II), a 400+ bed facility located in Sussex County, which garnered attention when the nursing home ended up on the front page of the New York Times: "*70 Died at a Nursing Home as Body Bags Piled Up. This is What Went Wrong.*"[24] Disability Rights NJ was familiar with this nursing home from pre-COVID-19 investigations and monitoring and knew it to be a problematic facility with many residents with disabilities – particularly mental health disabilities, intellectual and developmental disabilities, and traumatic brain injuries (TBI).

Using our investigatory and records authorities, we sent a letter dated April 18, 2020 to the administrators of Andover II and its sister facility, Andover Subacute and Rehabilitation Center I (Andover I), demanding information about the numbers of residents at both facilities with documented IDD, "Serious Mental Illness" (SMI), and/or TBI, as well as the number of residents with these diagnosis who died from COVID-19 since March 2, 2020.[25] Andover I and II (later Limecrest Subacute and Rehabilitation Center and Woodland Behavioral and Nursing Center, respectively) provided the information requested to Disability Rights NJ on May 13, 2020:

- Andover I:
  - Number of licensed beds: 159[26]
  - Number of residents with documented ID: 10
  - Number of residents documented with SMI: 84
  - Number of residents with documented TBI: 2
  - Number of residents who died from COVID-19 since March 1, 2020 with documented ID, SMI, or TBI: 9

- Andover II:
  - Number of licensed beds: 504[27]
  - Number of residents with documented ID: 37
  - Number of residents with documented SMI: 221[28]
  - Number of residents with documented TBI: 15
  - Number of residents who died from COVID-19 since March 1, 2020 with documented ID, SMI, or TBI: 41[29]

Believing that the health and safety of residents, including those with disabilities, at Andover I and II were at significant risk in April 2020, we asked Governor Murphy and then-Commissioner of the Department of Health Judith Persichilli, to consider interventions, including:

- **Personal Protective Equipment (PPE):** Recognizing that there may have been insufficient PPE in Andover I and II, we called upon the administration to ensure that staff and residents have the necessary PPE, in accordance with CDC recommendations, to limit the spread of the virus.

- **Communication with Families:** Recognizing that there were allegations regarding the lack of communications with families by Andover I and II, including notification of families where residents had died, we advocated for resident access to Tracfones or other personal cells phones to allow them to call their family members. In addition, we advocated that, consistent with the ADA, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act, residents with disabilities be allowed to designate a support person who would have access to them in the facility.

- **Staffing Levels and the National Guard:** · While media reports suggested that the ownership of Andover I and II believed that staffing levels were sufficient and continued to meet required levels, should the Department of Health's investigation show otherwise, Disability Rights NJ called upon Governor Murphy's administration to deploy the Army National Guard, including medics, to Andover I and II to meet the care needs of the residents of these facilities.

- **Receivership:** We also asked that, should the Department of Health verify the most egregious violations of state and federal law, the administration pursue the enforcement remedies outlined in N.J.A.C. 8:43-E-3.1; we urged the Department of Health to seek removal of the current management and the appointment of a receiver pursuant to N.J.S.A. 26:2H-42 and N.J.A.C. 8:43E-3.7 to remedy the conditions that represented substantial or habitual violations of the standards of health, safety or resident care.[30]

Because of our concerns about people with disabilities at Andover II, renamed Woodland Behavioral and Nursing Center (Woodland), Disability Rights NJ resumed in-person monitoring at Woodland during the summer of 2021 and escalated our work into an investigation early in 2022.[31] Through our advocacy, as well as the advocacy of others like the NJ Long Term Care Ombudsman (LTCO), the Department of Health took action that led to the relocation of all residents and the nursing home's closure in August 2022.[32]

In addition to our investigative work at Woodland, Disability Rights NJ also escalated our advocacy efforts with respect to individuals with IDD in nursing homes throughout 2021 and 2022. During this period, we met with the Department of Human Services, the State Medicaid agency, and DDD to gather additional information about the number of individuals with IDD in nursing homes as well as New Jersey's implementation of the federal PASRR requirements.[33]

During Spring 2022, Disability Rights NJ initiated our formal systemic investigation. Based on our monitoring activity at several nursing homes throughout New Jersey and our on-going conversations with the State, we determined we had probable cause to believe that individuals with IDD were subject to neglect and unnecessary segregation in these institutional settings. By letter to DDD dated April 6, 2022, we requested information about nursing homes where people with IDD may reside including: (1) the name of the facility; (2) the name of any resident with IDD; and (3) if the resident is known to have a

guardian, the name and any available contact information for that guardian.[34] On April 14, 2022, DDD produced a list with the names of 587 people with IDD in New Jersey nursing homes. After we reviewed the list, Disability Rights NJ was left with a list of 564 residents when we subtracted those without nursing home addresses, and 525 when we also subtracted residents of pediatric nursing facilities.[35] DDD informed Disability Rights NJ that the list was generated by correlating people in nursing homes with people who were receiving DDD services at the time they went into the nursing home, had been referred for services to DDD or had received services from DDD at some point in time.

PEDIATRIC NURSING HOMES

Information provided by the Department also contained concerning information about many very young people (ages 12 to 29 years) with IDD living in institutional pediatric nursing homes. The original list produced by DDD on April 14, 2022 included 39 individuals with IDD residing in one of New Jersey's four pediatric nursing homes: Children's Specialized Hospital – Mountainside (3 pediatric residents), Children's Specialized Hospital - Toms River (4 pediatric residents), Phoenix Center for Rehabilitation and Pediatrics (4 pediatric residents), and Voorhees Pediatric Facility (28 pediatric residents). We found that some of the "pediatric" residents were over the age of 21, with the oldest being 29 years old. We also observed, in separate monitoring of pediatric nursing homes, that many of the children attended school outside of the nursing home, either public school or out-of-district separate schools. While this investigation focused on adults with IDD living in nursing homes, we must also ask, "Why are children with IDD living in nursing homes in New Jersey rather than home and community-based settings,[36] especially with their families?"

With this information in hand, Disability Rights NJ designed our investigative methodology which included:

- Site visits to nursing homes, with a focus on the nursing homes identified by DDD as having the greatest number of residents with IDD as well as ensuring we visited nursing homes in all 21 counties.
- Efforts to observe and/or interview DDD-identified residents with IDD at nursing home site visits.
- Efforts to identify, in conversations with staff and residents, whether there were residents with IDD living at those nursing homes who were not identified in the DDD list.
- Collection of limited demographic data on both DDD-identified residents with IDD at nursing homes as well as residents identified solely through site visits and review of Face Sheets, PASRR screens, and other documents.[37]
- Opportunities for private guardians and Bureau of Guardianship Services guardians to be interviewed or complete surveys.[38]
- Referrals to our Institutional Rights Legal Team for individual legal representation for residents with IDD who told a Disability Rights NJ team member that they wanted to leave the nursing home, primarily to go to a home and community-based setting.
- Conduct legal research into relevant federal and state laws.

Disability Rights NJ dedicated significant resources to this project, including the Director of the Investigations and Monitoring Team, the Legal Director, and several attorneys and advocates. Ultimately, we made site visits to 71 nursing homes (including one pediatric facilities) and met with 357 DDD-identified nursing home residents with IDD, as well as several other individuals with IDD who were not on the list from DDD but were identified through our site visits. We met with and/or observed 68% of the individuals on the DDD list and at least 50% of the DDD-identified residents of each county.

During our site visits, we made efforts to observe the residents, interview those who consented to speak with us, and to gain their guardian's information, as applicable. We also spoke with social workers, directors of nursing, staff, and administrators, all as willing and available, and provided information and referral about our services. We asked for admissions data including Face Sheets and PASRR screenings.

Disability Rights NJ used a short questionnaire to guide our interviews with residents, including how they came to live in a nursing facility, how they liked living at their facility, what their day-to-day life is like, including food, activities, and time outside, and where they might want to live.[39] During these interviews, we also collected observational data on the conditions and overall environment of the nursing homes where the individuals reside. These initial interviews brought to light the circumstances of those with more extensive stories highlighted in this report.

Disability Rights NJ made several different efforts to contact private guardians, including obtaining names from the nursing facilities, through paper and on-line surveys, newsletters, social media, through our sister agencies, and by direct and targeted mail to 124 guardians who are family members or friends, inviting them to complete a survey asking questions about their family member's experience in their respective nursing homes.[40] Approximately 21 private guardians responded to the survey and were interviewed, if they indicated they wanted to be interviewed.

Approximately 61 individuals on the list have public guardians through the Bureau of Guardianship Services (BGS) or the Office of the Public Guardian (OPG). We sent a survey and interviewed over a dozen BGS and OPG guardians about their experiences in the current system and obtained history and information about the individuals to whom they provide guardianship. We requested admissions records and PASRRs of these individuals.

We also spoke with over a dozen stakeholders in the areas of intellectual and developmental disabilities and aging, including advocacy groups, non-profits, and trade organizations. Disability Rights NJ's sister agencies, the NJ Council on Developmental Disabilities, and the Boggs Center on Developmental Disabilities, the Ombudsman for Individuals with Intellectual or Developmental Disabilities and their Families, the New Jersey Long-Term Care Ombudsman, representatives of managed care organizations, I Choose Home New Jersey, Office of Community Choice Options (OCCO), OPG, AARP, Trinitas Medical Center, Leading Age NJ & Delaware, and BGS, seeking their concerns, observations, and recommendations.

Disability Rights NJ's data collection efforts reflected the use of multiple approaches with the overarching goal to obtain as much information as we could from these individuals, their guardians, family members, those involved in their care, and those who are stakeholders in the field. Our efforts were not aimed at precise scientific methods, but, nonetheless, reflect efforts at collecting a broad range of information using multiple approaches.

At the same time, Disability Rights NJ conducted in-depth research of all relevant laws and policies regarding the placement of individuals with IDD in nursing homes, as well as those procedures defined to serve as guardrails to both admission and discharge.

KEY FINDING NUMBER ONE:

The State of New Jersey has failed to collect and maintain complete, consistent, and accurate data regarding people with intellectual and developmental disabilities (IDD) residing in nursing homes, both pre-COVID-19 and since, and, to the extent they do have information, the State appears to be undercounting the actual number of people with IDD living in nursing homes. New Jersey cannot meet its *Olmstead* obligation to identify and divert or transition nursing home residents with IDD into home and community-based settings without this information. Moreover, publicly available federal data shows that nearly 20% of nursing home residents with IDD were no longer in nursing homes after the first, most deadly COVID-19 wave, and without complete, consistent, and accurate information we cannot know if that is because they left for other settings, if it is because they died, or some other reason.

Disability Rights NJ undertook this systemic investigation because we had anecdotal information, both before and after COVID-19, that nursing homes had somehow become the "new" institutional setting for people with IDD: we observed, and other advocates told us, that there were a substantial number of people with IDD of all ages and with different needs living in nursing homes. If true, this raised several serious alarm bells. First, the inappropriate institutionalization of people with IDD in nursing homes is a potential violation of the *Olmstead* decision and Title II of the Americans with Disabilities Act (ADA). [41] Nursing homes were dangerous places for all residents to live during the early months of COVID-19, and, as the Protection and Advocacy system (P&A) under the Developmental Disabilities Assistance and Bill of Rights Act (2000), [42] we were concerned about the health and safety of residents with IDD living in those institutions.

In order to do this work, and consistent with our investigatory powers under federal law, Disability Rights NJ needed a complete, detailed list of every person with IDD living in a nursing home in New Jersey. We now know that the list provided to us by the Division of Developmental Disabilities (DDD) on April 14, 2022 is not complete: based on comparisons with publicly available federal data discussed below, the list provided to us (as well as the information provided at the 2019 Medical Assistance Advisory Council or MAAC meetings) underreported the number of nursing home residents with IDD by a margin that remains uncertain, but could be between 24% and 37% during the periods reviewed. State partners from the Department of Human Services – the state Medicaid agency, DDD, the Division of Aging Services (DoAS) – were cooperative and helpful throughout, and seemed to want to provide the information we sought; however, we have concluded that accurate information simply does not exist.

Below, Disability Rights NJ sets forth the

DDD-generated data and federal data we examined as part of our investigation that informs Key Finding One, especially our finding that the State appears to be undercounting the actual number of nursing home residents with IDD. The conclusions to be drawn from this albeit incomplete data are that: [43]

- The State of New Jersey does not know how many residents with IDD are in nursing homes.
- The State of New Jersey does not collect and maintain important demographics (e.g., age, race, ethnicity, disability, language spoken, sexual orientation, or gender identity)[44] that would aid in examining implicit bias in the long-term care services and supports delivery system and assist state policymakers as they build out future opportunities to advance equity in home and community-based settings. [45]
- The State of New Jersey has no way to measure if they are missing opportunities for nursing home transitions under the federal demonstration Money Follows the Person (MFP), branded "I Choose Home NJ". [46]

Moreover, the State does not have failsafe mechanisms both to maintain critical information captured by the Preadmission Screening and Resident Review (PASRR) Level I and Level II screening (e.g., need for affordable, accessible housing especially for people with complex support needs and those with dual diagnoses)[47] and to ensure that PASRR Level II screens are completed for people entering the nursing home on Exempted Hospital Discharges or through time-limited Categorical Determinations to foster early transition back to the community or specialized services for those who need and choose nursing facility services. (See Key Finding Two, p. 27).

Most importantly, without accurate, reliable data, the State is at serious risk of violating the U.S. Supreme Court's *Olmstead* mandate to provide services in the most integrated setting appropriate to an individual's needs precisely because, without this information, they cannot develop and implement a "comprehensive, effectively working plan for placing" nursing home residents with disabilities, including IDD, in community-based programs.[48] Transparent data is also necessary so that people with IDD, their families, and their advocates, including Disability Rights NJ, can understand the landscape and zealously advocate for change where needed.

DISABILITY RIGHTS NJ'S ANALYSIS: FINDING ONE

1 DDD NURSING HOME RESIDENT DATA

As discussed in the previous section on the Investigation, the Division of Developmental Disabilities (DDD) provided information about the number of people with IDD in nursing homes on three occasions between 2019 and 2022.

- At the April 25, 2019 MAAC meeting, data was presented based upon the number of people with IDD on Managed Long Term Services and Supports (MLTSS) in nursing homes: the numbers from July 2014 through December 2018 ranged between 579 and 635 residents; [49]
- At the July 25, 2019 MAAC meeting, data was presented based upon the number of people with IDD in MLTSS and fee-

for-service: the numbers from July 2014 through December 2018 ranged between 582 and 638 residents.[50]

- On April 14, 2022, DDD produced a list with 587 names of people with IDD in nursing homes in response to Disability Rights NJ's formal request of which 564 had nursing facility addresses, and 525 were adults.[51]

While the State explained to us that different methodologies were used to gather the 2019 data and the 2022 data, the final numbers are substantially similar – the State could account for between approximately 564 and 638 residents with IDD in New Jersey nursing homes during this time period, 2014 through 2022.[52]

Note: Through our site visits and interviews with key stakeholders, Disability Rights NJ identified a limited number of additional nursing home residents with IDD not on the original DDD list.[53]

2 DDD PASRR DATA

In September 2022, Disability Rights New Jersey requested statistical PASRR data from DDD for the period of January 1, 2019 through December 31, 2021.[54] Subsequently, we made follow-up requests for 2022 and 2023 data through June 30, 2023.[55]

Note: For an in-depth explanation of the PASRR process, *see Key Finding Two, p. 27.*

Year	Level I IDD Positive - Referred to DDD[56]	Exempted Hospital Discharge[57]	Level II IDD Positve	Level II IDD Negative	Specialized Services Needed	No Specialized Services Needed
2019	515	252	597	4	25	576
2020	457	282	353	5	0	358
2021	476	271	410	9	1	418
2022[58]	725	292	693	17	1	709
2023[59]	406	195	335	0	0	390

In our analysis of the DDD-generated PASRR data, Disability Rights NJ is cautious not to draw over-reaching conclusions from this limited data set produced in response to written questions without the opportunity for us to review thoroughly with DDD. We nevertheless believe the data raises significant questions (some of which relate to Key Finding Two and the misapplication of federal PASRR law to the definition of specialized services by New Jersey, see Key Finding Two, p. 27) and that it suggests that the list of 564 people produced in April 2022 undercounts the actual number of people with IDD, though this data does not provide a clear sense of by what margin people are being undercounted. For example:

- From 2019 to 2022, between 457 and 725 Level I Positive PASRR screenings were referred to DDD, and in about half of those referrals, (between 252 and 292) the individual met the criteria for a 30-day Exempted Hospital Discharge which means that the person could go directly into a nursing home without a Level II screen. (See Key Finding Two, for discussion of Exempted Hospital Discharges) While we do not have data that says if they actually went into the nursing home on the Exempted Hospital Discharge status, it is fair to assume that most did and that some percentage of those individuals remained past 30 days, especially since DDD stated they do not track people admitted to nursing homes with a Level I Exempted Hospital Discharge status to ensure the Level II is done within 40 days if they remain. This data suggests that between 2019 and 2022, there were at least 252 new nursing home admissions annually for people with IDD on the 30-day Exempted Hospital Discharges.[60] *Note: Because we do not have complete data to know if those individuals left the nursing home prior to the 40 days or thereafter, or if they had a full Level II, there are potentially 'double-counted' individuals included in the next bullet.*

- From 2019 to 2022, Level II screenings confirmed the diagnosis of IDD in between 353 and 693 evaluations, and of those, most were also found to NOT need specialized services. Contrary to federal law, New Jersey's PASRR process defines specialized services such that a person found to need specialized services is barred from nursing home admission. (See Key Finding Two, for discussion of specialized services). While the New Jersey definition is legally backwards (under the federal definition specialized services are provided in a nursing home), here, it allows us to assume that most of the individuals who were found on the Level II screen to have IDD and not need specialized services ended up in a nursing home. This number may be, at least partially, in addition to the people admitted under Exempted Hospital Discharge status, but given the data we reviewed, we are uncertain.

- 2023 DDD-generated PASRR data suggests 195 nursing home admissions under Exempted Hospital Discharge status and 335 admissions to nursing homes of people with IDD who do not need specialized services in the first six months of 2023. *Note: Disability Rights NJ has insufficient data to know if there are duplications between these two numbers.*

Overall, the PASRR data provided to Disability Rights NJ by DDD strongly suggests the admission of between 252 and 693 new residents with IDD each year between 2019 and 2022. We do not have information about

resident discharges or deaths so cannot reach any conclusions with respect to the admission/discharge balance in total number of nursing home residents with IDD during this period.

3 MDS 3.0 DATA

The Long-Term Care Minimum Data Set (MDS), first enacted as part of the 1987 Nursing Home Reform Act, is a health status screening and assessment tool used for all residents of nursing homes certified to participate in Medicare or Medicaid, regardless of payer source. [61] The purpose of the MDS is: to assess nursing home quality and to help monitor the health and welfare of residents; to generate quality improvement measurements that nursing homes use internally and that state surveyors use in the survey and certification process; to help states assess the cost effectiveness of care protocols; to set long-term nursing home reimbursement rates; and to allow prospective residents and families to compare nursing home quality measures. [62]

MDS Version 3.0, implemented on October 1, 2010, has implications for residents, families, providers, researchers, advocates, stakeholders, and policymakers, all of whom have access to MDS data through the Centers for Medicare and Medicaid Services (CMS) Minimum Data Set Frequency Report. [63] The MDS Frequency Report summarizes information for residents currently in nursing homes by calendar quarter and consolidates information for each active nursing home resident into the report. The MDS 3.0 Frequency Report can be found here: https://data.cms.gov/quality-of-care/minimum-data-set-frequency

The MDS 3.0 assessment should be conducted by nursing home staff, under the supervision of an MDS coordinator for all nursing home residents within 14 days of admission, at quarterly and yearly intervals, and upon a significant change in condition. [64] Results are uploaded into the national database referenced above.

The revised 2010 MDS 3.0 added a PASRR-related question, A1500, which asks whether the nursing home resident has been identified as having a "mental illness" (MI), intellectual disability (ID), or a related condition (RC). [65] In April 2012, a second PASRR-related question was added, A1510, which requires respondents to indicate the diagnosis of any nursing home resident for whom A1500 is "yes" using the MI, ID, or RC indicators in the MDS. [66]

A1510. Level II Preadmission Screening Resident Review (PASRR) Conditions
Complete only if A0310A = 01, 03, 04, or 05

↓	**Check all that apply**
☐	A. Serious Mental illness
☐	B. Intellectual Disability
☐	C. Other related conditions

For example, if a resident has an intellectual disability, as defined in the PASRR regulations, the facility must code "1" (a "Yes" answer) in the box above next to "B. Intellectual Disability," or "0" (a "No" answer) if they do not have an intellectual disability. This produces the Yes and No percentages and totals on the MDS Frequency Report. Similarly, if the resident has an "Other related condition" as defined in the PASRR regulations, the facility must code "1" (a "Yes" answer) in the box above next to "C. Other related condition," or "0" (a "No" answer) if they do not have an "Other related condition." [67]

MDS FREQUENCY REPORT PASRR DATA FOR 2019 THROUGH 2023[68]

MDS - 3.0 Frequency Report Data for NJ				
Year	Quarter	A1500: Is the resident currently considered by the state level II PASRR process to have serious mental illness and/or intellectual disability or a related condition? A1510: Check all that apply:		
		A1510B: Intellectual Disability (total yes responses for NJ)	A1510C: Other related conditions (total yes responses for NJ)	Total of A1510B and A1510C*
2019	Jan-March 2019	726	248	797-974*
	April-June 2019	728	244	809-972*
	July-Sept 2019	685	221	755-906*
	Oct-Dec 2019	679	224	774-903*
2020	Jan-Mar 2020	668	223	756-891*
	April-June 2020	539	185	620-724*
	July-Sept 2020	575	183	642-758*
	Oct-Dec 2020	556	185	631-741*

2021	Jan-March 2021	555	189	626-744*
	April-June 2021	551	181	615-732*
	July-Sept 2021	567	192	636-759*
	Oct-Dec 2021	535	213	628-748*
2022	Jan-March 2022	540	204	641-744*
	April-June 2022	519	191	619-710*
	July-Sept 2022	542	203	644-745*
	Oct-Dec 2022	526	208	620-734*
2023	Jan-March 2023	522	226	624-748*
	April-June 2023	668	274	778-942*

***Note**: The totals in the last column are predictive, based on Disability Rights NJ's analysis of the MDS frequency data; the totals represent the possible range of people with IDD in nursing homes during each quarter reviewed. The lower number was calculated by adding the number of people who answered "yes" to A1510B (ID) and A1510C (RC) and subtracting out the highest possible number of duplicative "yes" answers (meaning that "yes" could have been recorded for both A1510B and A1510C). For all quarters reviewed, the potential duplicative "yes" answers to A1510A, A1510B, and A1510C was between 5% and 7% of the total number of "yes" answers to A1500. The larger number was calculated by adding together the number of people who answered "yes" to A1510B (ID) and A1510C (RC), and assumes no duplication between ID and RC (meaning all duplication would be attributable to a person answering "yes" to A1510A (MI) and either A1510B (ID) or A1510C (RC). Disability Rights NJ does not have access to specific information to know for certain the number of people with ID, RC, or both represented by the MSD data by quarter. [69]

By examining the CMS Frequency Report data related to PASRR questions A1500 and A1510, Disability Rights NJ observed discrepancies between the DDD-provided data, about 564 people with IDD residing in nursing homes, and the MDS 3.0 data, which averaged between 679 (lowest predictive number) and 804 (highest predictive number) people with ID, RC, or both, residing in nursing homes during similar periods of time. We found that the State was unaware of as many as 37% of the people with IDD residing in nursing homes in late 2018/early 2019 and 24% of the people with IDD residing in nursing homes in Spring 2022, using the highest predictive numbers.[70]

4 UNKNOWN OUTCOMES FOR PEOPLE WITH IDD IN NURSING HOMES AT THE BEGINNING OF THE COVID-19 PANDEMIC.

Disability Rights NJ observes that in the two quarters directly preceding the COVID-19 pandemic in New Jersey, nursing homes reported, through MDS 3.0 data, that there were at least 903 (Q4 2019) and 891 (Q1 2020) people with IDD residing in New Jersey nursing homes (using the highest predictive numbers). This number drops off precipitously the following quarter (Q2 2020), by a factor of more than 170 people with IDD. In Q2 2020 there were suddenly only 724 nursing home residents reported to have IDD (using highest predictive number). This represents a decrease of nearly 20% of the IDD population in nursing homes right at the beginning of COVID-19 and during those initial months when so many nursing home residents died.

Disability Rights NJ does not know the reason for this dramatic decline, and we encourage the State to investigate and understand what happened to these individuals: Did they return to family homes or other homes in the community? Were they hospitalized? Did they die?

May 2024 Update: Significantly, Disability Rights NJ points to the step increase in the number of people answering "yes" to MDS PASRR question A1510B and A1510C between the first quarter of 2023 and the final three quarters of 2023, trending toward to the pre-COVID levels of people with IDD in nursing homes:

2023	"Yes" A1510B (ID)	"Yes" A1510C (RC)
1st Quarter	522	226
2nd Quarter	668	274
3rd Quarter	673	277
4th Quarter	656	281

2023 MDS data suggests a 29% increase in the number of people with ID in nursing homes between the 1st and 3rd quarters (522 people with IDD v. 673 people with IDD), and a 24% increase in the number of people with RC between the 1st and 4th quarters (226 people with IDD v. 281).

Disability Rights NJ does not know if these increases, 151 additional people with ID and 55 additional people with RC represent unique individuals.

KEY FINDING
NUMBER TWO:

New Jersey's PASRR regulations and practices do not align with federal law and CMS technical assistance leading to: (1) the inappropriate and potentially unlawful institutionalization of individuals with IDD in nursing homes as well as a missed opportunity to engage in person-centered practices that result in nursing home diversion, transition, and increased opportunities for people with IDD to live in the community with individualized supports and services; and (2) the failure to provide people with IDD who need and choose the services of a nursing home with the specialized services they are entitled to receive under federal law.

The paramount finding from Disability Rights NJ's investigation is the failure of New Jersey, through its codification and implementation of the federal Preadmission Screening and Resident Review (PASRR)[72] requirements, to ensure basic compliance with the federal regulations[73] as well as implementation of NJ's PASRR process as an essential component in the State's *Olmstead* compliance strategy.[74] Through resident interviews, document review, input from guardians and other stakeholders, and legal analysis, Disability Rights NJ posits that New Jersey's PASRR failures have led, and are continuing to lead, to the inappropriate institutionalization of people with intellectual and developmental disabilities (IDD) in nursing homes rather than home and community-based settings (HCBS).

Moreover, for those individuals with IDD who choose and need the services of a nursing home, New Jersey law explicitly does not allow for the provision of "specialized services" that meet the unique and specific needs of a resident related to their intellectual or developmental disability in a nursing home, an indisputable violation of federal law.

These PASRR deficiencies are long-standing, going back decades, and, while they may have a historical foundation in the first several years of federal PASRR implementations, it is incumbent upon the Department of Human Services (DHS) to act with urgency to correct NJ's PASRR problems.

WHAT ARE SPECIALIZED SERVICES FOR IDD?

The most serious and detrimental PASRR failure in New Jersey law is the state's definitions of specialized services for "mental illness" (MI) and IDD. In all cases, the state defines the need for specialized services to preclude admission or continued stay in a nursing home. New Jersey law says that, for people with MI, specialized services can only be delivered in an inpatient psychiatric hospital, and, for people with IDD, specialized services can only be delivered in an Intermediate Care Facilities (ICF-IDD) or in a community-based setting which meets ICF-IDD standards.[75] Under federal law, specialized services are services provided to nursing home residents with IDD and MI, primarily in the nursing home but also through waiver-like specialized services in community settings as an *Olmstead* tool.[76]

Since the inception of the PASRR statute, there has been great confusion in state PASRR programs about "specialized services:"[77]

- **Are specialized services delivered exclusively in inpatient settings like state psychiatric hospitals and intermediate care facilities for people with IDD?**
- **Can and should specialized services be provided in nursing homes?**
- **Can specialized services be delivered in home and community-based settings?**
- **Can they be designed to mimic HCBS-waiver services to ensure continuity of care as well as nursing home transition?**
- **Who is responsible for delivering specialized services?**
- **Is the cost of specialized services included in the typical Medicaid daily nursing home rate?**
- **Can the state Medicaid agency use federal Medicaid dollars to pay for specialized services?**

The federal rule defines specialized services for IDD as follows:[78]

> For intellectual disability, specialized services means the services specified by the State which, combined with services provided by the nursing facility or other service providers, results in treatment which meets the requirements of [active treatment in an ICF-IDD as set forth in] §483.440(a)(1)…The State must provide or arrange for the provision of specialized services…to all nursing facility residents with…IDD whose needs are such that continuous supervision, treatment, and training by qualified…intellectual disability personnel is necessary, as identified by the [PASRR] screening.[79]

In 2013, CMS made clear that **specialized services may never be provided in an inpatient setting like a state psychiatric hospital or in an ICF/ID.** To the extent that states, including New Jersey, define specialized services to be services provided exclusively in these settings, those states' PASRR programs are out of compliance with the federal regulations.[80]

SPECIALIZED SERVICES CONTINUED

Rather, states must provide or arrange for the provision of specialized services[81] that are delivered in a nursing home as set forth in a resident's comprehensive person-centered care plan ("The comprehensive care plan must describe . . .[a]ny specialized services or specialized rehabilitative services the nursing facility will provide as a result of PASRR recommendations.")[82] States can also deliver waiver-like specialized services to nursing home residents in community-based settings, especially when designed as part of a continuum of care for individuals transitioning out of a nursing home back to their own homes or a community placement.[83]

While states determine what constitutes a "specialized service,"[84] in recent years, CMS has recognized that specialized services can be used to further continuity of care for those receiving HCBS waiver services in the community who are admitted to nursing homes and, for those in nursing homes who want to return to the community, especially those who have never received community-based services.[85]

Through guidance, CMS offers this definition: "Specialized Services are whatever disability specific services a given PASRR individual uniquely needs, above what the nursing [home] provides under standard reimbursement."[86] With this person-centered focus on the individual's unique needs, states may develop a list of commonly provided specialized services but must always look to the person with IDD's individual, **unique needs**.[87] CMS provides these examples:

- **Continuation or development of an individualized plan for habilitation, skill development, and behavior management.**
- **Continuation or development of a day or vocational program.**
- **Development/implementation of positive behavior supports plan, emergency safety interventions, and support/consultation to reduce negative behaviors.**
- **Additional one-on-one time with qualified IDD professionals to maintain independence with choice, activities of daily living, and other functional skills as well as provide advocacy, mode of communication, and communication with family.**

Through this definition and these examples, one can clearly see how CMS has expanded on the formal regulatory definition to encourage states to use PASRR to both amplify person-centered practices and facilitate nursing facility diversion and transition.[88]

Finally, state Medicaid agencies can receive technical assistance through the PASRR Technical Assistance Center (PTAC) on payment options available, through State Plan Amendment to Appendix 4.19 of a State Plan, including the provision of waiver-like specialized services.[89]

OVERVIEW OF FEDERAL PASRR REQUIREMENTS

HISTORY OF FEDERAL LAW

The federal requirements for PASRR were enacted as part of the Nursing Home Reform Act of 1987 (NHRA)[90] to ensure that people with mental health disabilities and intellectual disabilities or related conditions are not inappropriately placed in nursing homes for long term care.[91] While the statutory requirements of PASRR obligated states to implement their PASRR systems by January 1989, the PASRR regulations were not finalized until November 1992, leading to great variation and misapplication of the law that still exist in state PASRR systems.[92] In 1997, the PASRR statute was amended to repeal the requirement for an annual resident review and to require resident reviews for residents with "mental illness" (MI) or intellectual disabilities/related conditions (IDD)[93] only when there is a significant change in a resident's physical or mental conditions.[94]

While the PASRR regulations[95] have undergone some limited revision in the intervening 30+ years, the Centers for Medicare and Medicaid Services (CMS) did not publish proposed rules to significantly update and modernize the PASRR regulations until February 2020, just as the COVID-19 pandemic began:[96]

> This proposed rule would modernize the requirements for Preadmission Screening and Resident Review (PASRR), currently referred to in regulations as Preadmission Screening and Annual Resident Review, by incorporating statutory changes, reflecting updates to diagnostic criteria for mental illness and intellectual disability, reducing duplicative requirements and other administrative burdens on State PASRR programs, and making the process more streamlined and person-centered.[97]

While never adopted, the background and provisions of the proposed regulations in the proposed rule help explain CMS's evolutionary thinking about the purpose of PASRR post-*Olmstead* and the many changes and adaptations to the PASRR process in the years since 1992.[98]

In addition to the PASRR statute and regulations, CMS sub-regulatory technical assistance as well as other federal laws have molded PASRR best practices in effect today. In 2009, CMS established the PASRR Technical Assistance Center (PTAC) in response to CMS Inspector General reports in 2001 and 2007, which identified the need for strategies to standardize and improve PASRR implementation across the states.[99] Through guidance found on the PTAC website, it is clear that other federal laws have greatly impacted CMS's interpretation of the federal PASRR regulations as well as the potential for PASRR best practices leading to more focused person-centered planning and better integration and continuity of care across the healthcare spectrum, including:

- 1990: The Americans with Disabilities Act
- 1999: *Olmstead v. L.C.*
- 2005: Money Follows the Person (reauthorized in 2010)
- 2010: Implementation of MDS 3.0 which included PASRR-specific questions for the first time (additional PASRR questions added in 2012)
- 2013: CMS highlight of specialized services in nursing homes and flexible payment options
- 2014: HCBS Person-Center Planning Rule
- 2016: Amendments to nursing home regulations to require nursing homes to include specialized services in comprehensive person-centered care plans

PURPOSE OF THE FEDERAL PASRR REQUIREMENTS

The primary purpose of the PASRR requirement is to ensure that people with mental health disabilities and/or intellectual disabilities/related conditions are not inappropriately placed in nursing homes for long-term care.[100] To meet this purpose, the law requires state PASRR systems to:

- Evaluate all applicants for "mental illness" (MI) and/or intellectual disabilities/related conditions (IDD) prior to admission to a nursing home as well as upon a significant change in condition.
- Offer applicants to nursing homes or residents experiencing a significant change in condition the most appropriate setting for their needs and desires (e.g., the community, a nursing home, an acute care setting like a hospital), with an emphasis on the least restrictive setting.[101]
- Provide individuals with MI/IDD with all the services they need, including specialized services in a nursing home.[102]

Since 1999, a significant and powerful function of PASRR has been to foster *Olmstead* principles through diversion from the nursing home front door and transition out of the nursing home back to home and community-based settings and services.[103] To this end, CMS encourages states to adapt PASRR systems to: support and advance existing state initiatives (e.g., Money Follows the Person, Section Q of the MDS, HCBS waivers);[104] promote continuity of care; support recovery; reflect person-centered thinking and planning; emphasize community integration and placement in the least restrictive setting; and promote the empowerment of the individuals with disabilities.[105]

FEDERAL PASRR CODE OF FEDERAL REGULATIONS (CFR) PROCESS[106]

The PASRR process described below applies to all people with MI or IDD who apply to or reside in a Medicaid-certified nursing home regardless of source of payment prior to admission to a nursing home and upon a significant change of condition.[107]

Moreover, the process is unique under the Medicaid Act, because it is a partnership among the state Medicaid agency, the state mental health authority, and the state intellectual disabilities authority and assigns responsibilities to each.[108]

The PASRR process is a two-step process: the Level I Preliminary Screen and Level II Evaluations and Determinations.

LEVEL I: PRELIMINARY SCREEN

The PASRR Level I is the preliminary screen which is used to identify all applicants to or residents of nursing homes who are suspected of having an MI or IDD as defined under the regulations.[109] Every applicant to a Medicaid-certified nursing home must have a Level I screen to determine if they have a possible MI or IDD.[110] If the Level I screen results indicate that an individual has a possible MI or IDD -- the Level I is "positive" – then the individual must be referred to the state mental health or intellectual disability authority for the Level II screening and the

applicant or resident (and legal representative, if there is one) must be provided a written notice that they are being referred for a Level II Evaluation and Determination.[111] An individual who has a "positive" Level I screen may not be admitted to a nursing home until the PASRR screening process is complete.

While the regulations do not provide detailed criteria or recommendations for the Level I screening tools, CMS recommends that states should be in a continuous process of review and revision of these evaluation tools to ensure the tools meet best practices. CMS recommends that states include questions that seek to identify MI or IDD that has not previously been reported and look beyond reported diagnoses such as dementia.[112] States should be particularly concerned about Level I false negatives, a screen that does not identify an individual who should be referred for the Level II evaluation. States also need to pay attention to the measures and process they use to track the quality of Level I Preliminary Screens.[113]

LEVEL II: EVALUATION AND DETERMINATION

The Level II process includes an in-depth evaluation and determination.[114] CMS views the Level II evaluation as the front line for ensuring that people with MI and IDD are diverted from unnecessary admission to nursing homes and for promoting access to services and supports to facilitate transition to more integrated settings in the community.[115] Accordingly, the Level II evaluation process and criteria must be individualized and person-centered: it must include the person being evaluated to the greatest degree possible, their families and supports if the person agrees to the same, and it must be adapted to the cultural background, language, ethnic origin and means of communication used by the person being evaluated.[116] Under no circumstances, should the PASRR process be a "desk review" of medical or clinical records.[117]

The individualized PASRR evaluation must first confirm or disconfirm a MI or IDD diagnosis,[118] and the evaluation may be terminated if the evaluator finds that the person does not have a MI or IDD.[119] If the MI or IDD diagnosis is confirmed, the evaluation process should include the following memorialized in a report:

- A summary of the medical and social history, including positive traits and developmental strengths and weaknesses or developmental needs of the person evaluated;
- Identification and recommendations of appropriate treatment and placement options and services;
- If nursing facility level of services are needed and recommended, the specific services which are required to meet the person's needs including any specialized services to be provided in the nursing home;
- If specialized services are not recommended, any specific IDD or mental health services which are of a lesser intensity than specialized services that are required to meet the person's needs (e.g., specialized rehabilitative services); and
- If specialized services are recommended, the specific IDD or mental health services required to meet the person's needs.[120]

The Level II Evaluation is an integral part of determining setting options and a person's plan for services (regardless of where they are "placed").[121] The federal regulations emphasize that the evaluator must assess the need for "NF [nursing facility] services and NF level of care"[122] as the basis of the determination regarding options for placement [123] and services.[124] The basic rule first requires the evaluator to assess whether the person's total needs are such that they can be met in an appropriate community setting or are such that while the individual meets a nursing facility level of care,[125] there are home and community-based Medicaid waiver programs available to that individual.[126] Only then can the evaluator assess for whether a nursing home is an appropriate setting (because the person needs nursing facility services and chooses that setting) or the person might need an acute setting.

If a person with IDD enters or resides in a nursing home, the Level II Evaluation, including applicable specialized services, must be incorporated into the routine resident assessments that become part of the person's individualized interdisciplinary plan of care.[127] This PASRR requirement is an example of how an "old" regulation intersects with newer federal requirements: a 2016 amendment to the rules governing nursing homes now requires nursing homes to develop and implement a "person-centered comprehensive care plan" that includes the specialized services or specialized rehabilitative services a nursing home will provide as a result of a PASRR recommendation. Embedded in this federal rule governing requirements for nursing homes is a presumption that state Level II evaluations and determinations will include recommendations for specialized services in nursing homes. [128]

The Level II Determination, which is derived from the evaluation, is a legal document including both specific information about the evaluation results as well as specific rights regarding a person's right to file an appeal.[129] It must be sent to the individual with MI or IDD as well as other enumerated individuals. [130] The Determination Notice must include: [131]

- A summary of the person's evaluation information;
- The target condition (MI or IDD) which is present;
- Whether or not nursing facility services are needed and appropriate; [132]
- Whether specialized services are needed;
- Alternative options to nursing home placement that are appropriate to the determination; [133]
- What services and supports would be necessary to support the person in the community, regardless of of availability of those services; and **regardless of availability of services;** and
- Appeal Rights [134]

Note regarding Resident Reviews: While the federal regulations have not been updated to remove references to annual review since 1997, the PASRR statute requires resident reviews upon a significant change in the resident's physical or mental condition that affects the individual's disability-specific needs such that a change of condition for a resident with MI or IDD should result in a referral to the state mental health or intellectual disability authority to conduct resident review evaluation and determination. [135]

Appeal rights for PASRR Level II Evaluations and Determinations are found at 42 CFR 431, Subpart E, the general provisions for Medicaid fair hearings, not in the PASRR regulations. The appeal rights laid out in 42 CFR 431, Subpart E related to PASRR apply to all applicants to or residents of Medicaid-certified nursing homes regardless of the resident's source of payment. *Note: 42 CFR 431, Subpart E also provides appeal rights to residents of Medicare and Medicare-certified nursing homes subject to an involuntary transfer or discharge from the nursing home.*[136]

EXCLUSIONS TO THE FULL PASRR LEVEL I AND LEVEL II PROCESS

The federal law allows states to opt for two exclusions to full PASRR process: "Exempted Hospital Discharges"[137] and "Categorical Determinations."[138] It is important to note that because these exclusions can circumvent the full Level II Evaluation and Determination process, there is a serious risk that they will be misused, which can lead to the over-institutionalization of people with IDD. Additionally, the failure to complete a necessary Level II evaluation, which could potentially recommend specialized services in a nursing home, could lead to an individual's decompensation and loss of necessary skills to transition and thrive in an HCBS setting.

Exempted Hospital Discharges: At a state's option, an individual may be temporarily exempted during the Level I screen from the Level II PASRR process if the person seeking admission to the nursing home directly is coming from a hospital.[139] This exemption is time-limited to 30 days. The person's doctor must certify to the Exempted Hospital Discharge criteria, and, if the person is later found to need more than 30 days of nursing facility care, the State mental health or intellectual disability authority must complete the Level II resident review within 40 calendar days of admission.[140] Notice of the Exempted Hospital Discharge and the potential for a Level II evaluation is required.[141]

While not required for Exempted Hospital Discharges, CMS recommends a best practice of completing the Level I screen for tracking purposes and beginning the Level II evaluation as a precaution. *Note that a nursing home level of care determination (aka clinical eligibility determination) is required for Medicaid recipients.*[142]

Note: The federal regulations also provide for a dementia exclusion for MI.[143]

Categorial Determinations: The federal regulations anticipate that Level II Evaluations and Determinations generally will be individualized and person-centered, though it allows for group Categorical Determinations.[144] Optional Categorical Determinations must be identified in a State Plan Amendment (4.39A) and approved by CMS.[145] Because Categorial Determinations permit an abbreviated evaluation and determination[146] and thus are another way to potentially limit the full PASRR Level II process, they should be critically assessed to ensure they are not overused or used in a manner to limit the delivery of specialized services to people in nursing homes who, despite "fitting" a Categorical Determination, would nonetheless benefit from specialized services.

The federal law permits both time-limited Categorical Determinations and advanced determinations that are not time-limited but must be monitored for changes in conditions. Examples are:

- Provisional Time-limited [147]
  - Adult Protective Services (APS) (may not exceed 7 days)
  - Respite (brief and finite timeframe specified by the State)

  Important - Specialized Services: For time-limited Categorical Determinations, the law permits a decision that specialized services are not needed based on category during the time-limited period.

- Advanced Determinations [148]
  - Terminal Illness/Hospice
  - Severe Physical Illness
  - Dementia and IDD [149]

  Important - Specialized Services: For Advanced Determinations, the law requires an individualized determination regarding specialized services even though the full evaluation is not required absent an improvement in condition.

Both Exempted Hospital Discharges and Categorical Determinations are bureaucratically complicated and open the door for poor quality controls in the PASRR process. The 2020 proposed federal regulations, which were never adopted, sought to simplify and correct some of the issues around these exclusions.[150] However, national advocates as well as Disability Rights NJ had serious concerns that some of the proposed changes would not simplify the current process or close loopholes, but in fact would extend the instances when hospitals, nursing homes, and state agencies could circumvent the PASRR process to the detriment of people seeking admission to or living in nursing homes, especially people with IDD. [151]

DISABILITY RIGHTS NJ ANALYSIS: FINDING TWO

Disability Rights NJ found that New Jersey's PASRR process is irrevocably broken: it neither achieves basic compliance with the federal regulations nor is it implemented as an essential component of the State's *Olmstead* compliance strategy. As discussed above (see Key Finding Two, Specialized Services box, p. 28-29), the most grievous legal error is New Jersey's definition of specialized services, though the problems are multifaceted. The result is that too many people with IDD, as well as people with mental health disabilities, end up institutionalized in nursing homes ill-equipped to meet their needs rather than home and community-based settings with the supports and services they need.[152] Moreover, New Jersey denies residents the specialized services they may be entitled to receive in the nursing home, services which could both improve their lives while there and facilitate their transition to more integrated community-settings.

We came to these findings which are discussed more below through all of the methodologies brought to bear in this investigation: review of federal law, review of New Jersey law and practices, nursing home site visits and interactions with residents with IDD, review of PASRR documents, and input from guardians and key stakeholders which we discuss below.

EXAMPLES OF HOW SPECIALIZED SERVICE DETERMINATIONS ARE MISUSED

The concepts of CFR regulatory compliance and PASRR as an instrument in the State's *Olmstead* plan discussed below are complicated and inextricably connected – each discussion relies on having read and understood the other discussion. To help illustrate these problems, below we provide examples of serious PASRR deficiencies, both from a CFR compliance and from an O*lmstead* perspective, that we found in the PASRR documents reviewed. [153]

Our review of PASRR Level I, Level II, and Resident Review documents included different iterations of the forms used by the State and DDD over the course of many years. Over time, the forms improved and reflected a better adherence to federal law. The most recent DDD Level II screening forms are from March 6, 2020. Nevertheless, these forms do not adhere to basic regulatory compliance or an *Olmstead* strategy for reasons that include: no evidence that the evaluation forms require review of current, accurate, and sufficient data (e.g., hospital records, physician's evaluations, review of community IDD providers records);[154] both the evaluation form and the determination form instruct the evaluator to "STOP" after making a Categorical Determination including an Advanced Categorical Determination (incorrectly called an "exemption") and prior to the review for specialized services, even though the federal law is clear that for terminal illness and severe physical illness Categorical Determinations, DDD must still do a more extensive individualized evaluation for specialized services; evaluation form is not clear if the individual themselves participated; the determination that an individual would benefit from specialized services only allows for specialized services in the community, not in the nursing home; the Determination Notice form does not include the alternative options to nursing facility placement or services and supports necessary to support individuals in the community regardless of availability of those services.

Copies of the PASRR Level I, Level II and Resident Review forms currently used for individuals with IDD can be found here: https://disabilityrightsnj.org/whats-happening-now/person-first-nursing-homes-report/

- An individual in their 40s who lived in a group home went into a nursing home from the hospital on Exempted Hospital Discharge status and remained in the nursing home for more than 40 days without a full Level II Evaluation and Determination. After more than 6 months, an abbreviated Level II screen was completed which indicated the individual met the criteria for one of the Advanced Categorical Determination categories. However, as set forth in the NJ PASRR Level II Determination Notification form used, the determination stops (there is an icon of a stop sign on the form) after checking off the box for the applicable category and the next section,"Specialized Services Recommendations," is blank, suggesting that an individualized evaluation was not done. Federal law requires a more extensive individualized assessment to determine the exact nature of the specialized services that are needed in these circumstances.[155] Disability Rights NJ found this general pattern – a finding that a person met the criteria for an Advanced Categorical Determination but

no evidence of a more extensive individualized evaluation for specialized specialized services – in dozens of PASRR documents reviewed.

- An individual with IDD living in their own apartment on MLTSS was referred for a Level I screen because she was not receiving necessary services in the community. It is unclear if they were assessed for DDD-specific services through the DD Supports or Community Care Program waivers prior to placement in a nursing home.

- Several individuals found to meet the criteria for the Advanced Categorical Determinations "Terminal Illness" with a life expectancy of no more than 6 months were still living in nursing homes more than two years later, with no indication they had been evaluated for specialized services as required by federal law.

- An individual initially on Exempted Hospital Discharge status was found to not meet the criteria for a Categorical Determination, to not need specialized services, but to meet criteria for "custodial care" in a nursing home pending transition to a community placement. The individual was moved from a DDD waiver program to MLTSS. The Determination Notice did not indicate that the individual received options counseling, nor did it identify community-based services and supports that would meet the person's needs, even if those services were not available at the time.

- Several individuals were found not to meet the criteria for an Exempted Hospital Discharge on the Level I screen, nor a Categorical Determination on a Level II screen and yet were found nursing facility eligible with no specialized services needed because nursing home services were "medically necessary" as if as if that was an allowable category under federal law.

- Several PASRR Level II Determinations reviewed made no finding for a Categorical Determination and that the person did not need specialized services but did need the services of a nursing home. However, Evaluation Reports were not part of the documents produced to Disability Rights NJ so we could not determine the basis of the need for nursing services or whether less restrictive community-based settings were considered.

- Overall, evaluators notes and PASRR forms refer to Categorical Determinations as "exemptions." This is incorrect under federal law, and matters because Exempted Hospital Discharge determinations made during Level I screenings are exempt for a period of time from the full process, but Categorical Determinations are not as they are either time-limited or do require individualized evaluations for specialized services.

- We found no evidence that the Level II Evaluation and Determination ever includes specialized services to be provided in the nursing home, though the form does theoretically capture specialized services in home and community-based settings.[156]

- We found not evidence that the Level II Evaluation and Determination ever identifies alternative options to nursing home placement that are appropriate to the determination or spell out what services and supports would be necessary to support the person in the community, regardless of availability of services.[157]

BASIC COMPLIANCE WITH FEDERAL LAW

The CFR compliance problems we identified have their source in a fundamental misapplication of the federal law in New Jersey PASRR-related statutes and regulations, primarily in the laws that set forth the definitions and protocols for "preadmission screening" and in the definition of "specialized services."

1 The term "preadmission screening" in New Jersey law co-mingles several distinct federal Medicaid requirements causing confusion and misapplication of the federal PASRR law under New Jersey law.

In 1988, likely in response to the enactment of the federal Nursing Home Reform Act and PASRR requirements in 1987, New Jersey enacted N.J.S.A. 30:4D-17.10 through 17.13 which establishes a "preadmission screening program" for potential nursing home residents to "determine the needs of Medicaid-eligible and other individuals seeking admission" to a nursing home, prior to placement in the facility.[158] The law defines a preadmission screening to mean: an initial evaluation to determine eligibility for the preadmission screening program, preparation of an assessment of a person's need for care in a nursing home including formal and informal support systems, and preparation of an initial care plan and arrangement of services.[159] The law also specifies that the nursing home is responsible for ensuring that the preadmission screening has been done with respect to each applicant to the facility who is Medicaid-eligible or will become Medicaid eligible within six months of admission.[160]

This law is woefully outdated and fails to encompass the many changes to federal law related to nursing home residents since it was enacted in 1988. A significant source of confusion is that the preadmission screening statute seemingly intermingles several distinct requirements of federal law: the requirement that Medicaid-eligible nursing home residents meet a "nursing facility level of care" (i.e., meet clinical eligibility criteria),[161] the requirement that nursing homes conduct resident assessments and care planning,[162] and the PASRR requirements that apply to all applicants to Medicaid-certified nursing homes, regardless of their payor source.[163] This is a problem because the statute sets the framework for the New Jersey regulations that govern both the process for Medicaid clinical eligibility determinations and the PASRR Level I and Level II determinations, and those regulations co-mingle these distinct federal requirements in a way that is convoluted and confusing and most significantly, gets the federal PASRR law wrong.[164]

Title 8 Health, Chapter 85 Long-Term Care Services of the New Jersey Administrative Code[165] includes the procedural requirements for both the Medicaid clinical eligibility determination process for nursing homes[166] and the PASRR process. Under New Jersey law, the "Pre-Admission Screening" or PAS process includes both the PAS process related to clinical eligibility determinations as well as the PAS process related to preadmission screenings and resident reviews.[167] In other words, PASRR requirements are subsumed within in the PAS regulatory process.[168] This framework does not make sense under federal law and is confusing for many reasons, with one example highlighted by the regulatory definitions:[169]

"Preadmission screening (PAS)" means the process by which **all Medicaid eligible beneficiaries** seeking admission to a Medicaid certified NF and individuals who may become Medicaid eligible within six months following admission to a Medicaid certified NF receive a comprehensive needs assessment by professional staff designated by the Department to determine their long-term care needs and the most appropriate setting for those needs to be met, pursuant to N.J.S.A. 30:4D-17.10. (P.L. 1988, c.97).

"Pre-admission screening and resident review" or "PASRR" means the process by which an individual meeting the clinical criteria for mental illness (MI) or mental retardation (MR/RC), **regardless of payment source**, is screened prior to admission to an NF to determine the individual's appropriateness for NF services, and whether the individual requires specialized services for that individual's condition and, therefore, is ineligible for NF services. PASRR includes two distinct processes, Level I screen and Level II evaluation and determination.

It seems obvious from the definition of PAS above that New Jersey meant the PAS process set forth in N.J.A.C. 8:85-1.8 to encompass the requirement and process to determine that potentially Medicaid-eligible nursing home residents meet a "nursing facility level of care" or are clinically eligible for Medicaid. [170] This is a function of the state Medicaid agency, and in New Jersey it is delegated by the Division of Medical Assistance and Health Services (DMAHS) to the Office of Community Choice Options (OCCO) in the Division of Aging Services or a Medicaid recipient's Managed Care Organization (MCO).[171]

However, **the PASRR requirements apply to all applicants or residents of Medicaid-certified nursing homes, not just those who are or will shortly be Medicaid eligible.** In addition, the authority for ensuring that Level I and Level II screens are completed rests not with the state Medicaid agency (DMAHS) but with the state mental health and intellectual disabilities authorities, the Division of Mental Health and Addiction Services (DMHAS) and Division of Developmental Disabilities (DDD) respectively in New Jersey.

The New Jersey PAS and PASRR statute and regulations are so outdated at this point that they do not implement PASRR requirements as required by the federal law which has significantly evolved since 1987.

2 New Jersey defines "specialized services" for both MI and IDD to explicitly exclude placement in a nursing home which is the exact opposite of the federal PASRR definition.

New Jersey law is replete with definitions of specialized services for MI and IDD which are contrary to federal law. [172] The source of these outdated and incorrect definition is likely the definitions set forth in Attachment 4.39 to the New Jersey Medicaid State Plan.[173]

DDD: Specialized Services are required when an individual is determined through the PASRR process to have skill deficits or other specialized training needs that necessitate the availability of trained IDD personnel, 24 hours per day, to teach the individual functional skills. Specialized services are those services needed to address such skill deficits or specialized training needs. **Specialized services may be provided in an ICF/ID or in a community-based setting which**

meets the ICF/ID standards. Specialized services go beyond the range of services which a NF is required to provide.

DMHAS: Specialized services are offered when an individual is experiencing an acute episode of serious mental illness and **psychiatric hospitalization is recommended**, based on a Psychiatric Evaluation. Specialized Services entail implementation of a continuous, aggressive, and individualized treatment plan by an interdisciplinary team of qualified and trained mental health personnel. During a period of twenty-four hour supervision for the individual, specific therapies and activities are prescribed, with the following objectives: a) to diagnose and reduce behavioral symptoms; b) to improve independent function; and c) as early as possible, to permit functioning at a level where less than specialized services are appropriate. Specialized Services go beyond the range of services which a nursing facility is required to provide.

This misapplication of federal law, which explicitly defines specialized services as services provided in a nursing home, is reflected throughout New Jersey regulations which explicitly state that specialized services for MI or IDD may not be provided in a nursing home.[174]

What the data showed (see table below)**:** The DDD-aggregate PASRR data and the individual PASRR documents Disability Rights NJ reviewed demonstrated that all of the individuals with IDD screened through the Level II Evaluation and Determination process were found **not** to need specialized services **in a nursing home**.[175]

The table below, that includes DDD-aggregate PASRR data, shows that nearly 100% of the individuals found to have a diagnosis of IDD on the Level II screen were also found not to need specialized services (which under New Jersey's backwards definition of specialized services means they can go into a nursing home), and it is reasonable to conclude that these individuals were admitted to a nursing home based on our review of PASRR documents: [176]

Year	Level II IDD Positive	Level II IDD Negative	Specialized Services Needed [177]	No Specialized Services Needed
2019	597	4	25	576
2020	353	5	0	358
2021	410	9	1	418
2022	693	17	1	709
2023	335	0	0	390

While we did not review data that would show how many individuals were receiving DDD services through the Supports or Community Care Program waivers prior to nursing home admission, it is also reasonable to conclude that most were and, most needed IDD-specific services and supports prior to entering the nursing home. This raises serious questions: **Did these same individuals suddenly no longer need IDD-specific services upon nursing home admission? Might they not benefit from specialized services in the nursing home, services that could help them transition back to the community more easily?**

It is not a far reach to conclude that New Jersey's backwards definition of specialized services may be leading evaluators to erroneously "find" that a person does not need specialized services in order to facilitate the nursing home admission, as to do otherwise would prohibit the admission under current state law. If true, this is problematic on many levels: first, the PASRR process appears devoid of true person-centered involvement and individualized recommendations that include choices for community-based settings (e.g., group homes, supported apartments) with the necessary, individualized services to support living in the community; and second, denial of specialized services in a nursing home to people with IDD who choose and need nursing home services ignores their history of receiving these services.

Another terrible consequence is also true: because so many people with IDD end up in nursing homes contrary to their expressed preference and without identified HCBS alternatives, they too are denied the benefit of specialized services, especially waiver-like specialized services designed to provide skills and supports needed to transition as soon as possible to home and community-based settings. [178]

PASRR AS AN ESSENTIAL COMPONENT IN THE STATE'S *OLMSTEAD* STRATEGY

Our investigation led Disability Rights NJ to conclude that New Jersey's PASRR process is little more than a rubber-stamp for nursing home admission that rarely, if ever, achieves anything close to an individualized, person-centered process that prioritizes home and community-based settings and services: it simply must be done to comply with federal law and facilitated Medicaid reimbursement for residents in nursing homes, particularly residents with MI or IDD. It is clear that the State has not designed and implemented PASRR as an essential component in its *Olmstead* strategy to minimize unnecessary nursing home placement for all people, including those with MI and IDD, and ensure that people live in the most integrated setting appropriate for their needs. [179]

OVER-RELIANCE ON PASRR EXCLUSIONS:

The PASRR data Disability Rights NJ reviewed suggests an over-reliance on optional Exempted Hospital Discharges and Categorical Determinations by New Jersey without the counterbalance of a rigorous process to ensure that time-limited exclusions are revisited and where individualized evaluations are required, especially for specialized services, that they happen. For example, at the Level I screening, New Jersey screens for Exempted Hospital Discharges, yet DDD told Disability Rights NJ that it does not have the data for the number of Level II Evaluations and Determinations processed by day 40 for these admissions that extend past 30 days.

(Note: Disability Rights NJ is not concluding that the follow-up Level II screen goes undone; in fact, we reviewed some PASRR documents that did show Level II screens within 40 days). Significantly, the data reviewed showed that on average over five years, approximately 50% of the applicants to nursing homes with IDD between 2019 and 2023 entered the nursing home on an Exempt Hospital Discharge.

New Jersey also opts for Categorical Determinations in its Medicaid State Plan including: dementia with IDD, terminal illness, severe physical illness, respite care, and protective services.[180] Here too the data suggests that consistently more than 40% of the Level II screens that confirm the diagnosis of IDD also find that the person with IDD meets the criteria for a Categorical Determination, and thus received an abbreviated Evaluation and Determination. PASRR documents reviewed also showed that evaluators were explicitly told to "STOP" after making Advanced Determinations of Terminal Illness and Serious Physical Illness, thus skipping the questions about specialized services altogether, suggesting that no individualized evaluations were being made for specialized services even though the federal law requires them.[181]

CMS cautions that Exempted Hospital Discharges and Categorical Determinations are risky and can result in a PASRR process that: is not individualized; does not promoted the most integrated setting appropriate for individuals; and does not provide specialized services that nursing home residents with IDD are entitled to receive.

EXEMPTED HOSPITAL DISCHARGES FROM DDD-AGGREGATE DATA:

Year	Level I IDD Positive	EHD #	EHD %
2019	515	252	49%
2020	457	282	62%
2021	476	271	57%
2022	725	292	40%
2023 [182]	406	195	48%

Appeals: Disability Rights NJ also reviewed the DDD-aggregate data with respect to the number of appeals. Fewer than 10 appeals were filed between 2019 and 2023. This number is so low as to suggest that people do not understand the significant rights at issue. For example, when a person is found not to need specialized services when they do, no appeal is filed.

CATEGORICAL DETERMINATIONS FROM DDD DATA:

Year	Level II IDD Positive	Terminal Illness	Serious Illness	Respite	APS	Dementia	Total CD	% CD
2019	597	8	146	19	1	77	252	42%
2020	353	4	103	4	0	51	162	45%
2021	410	6	122	7	1	44	18	43%
2022	599	11	182	3	1	57	254	42%
2023 [183]	335	1	56	1	0	22	153	45%

SPECIALIZED SERVICES AS AN *OLMSTEAD* TOOL:

Disability Rights NJ has explained the problem with New Jersey's definition of specialized services which directly impacts the State's ability to use them as powerful *Olmstead* tools. However, CMS encourages states to use State Plan Amendments to adopt specialized services to achieve *Olmstead* goals with an emphasis on continuity of care.[184] Waiver-like specialized services can be designed for both people with IDD on DDD waivers who need short stays in nursing homes (to allow them to keep intact pre-existing community-based services, like adult day habilitation or attain new specialized services focused on transition) and long-term residents with IDD who need to gain skills to return to the community.[185]

Examples from other states include:

- Connecticut: Day Services Group, Individualized Day Services, Habilitative Behavior Support and Coordination, Clinical Services for developing a behavioral support plan.[186]
- Washington: Assistive Technology, Community Access, Community Guide Services.[187]
- Nebraska: Habilitative Skills Support and Employment Assistance.[188]
- Texas: Behavioral Supports, Day Habilitation, and Independent Living Skills.[189]

HOUSING AND INDIVIDUALIZED SERVICES AND SUPPORTS AS A BARRIER:

While this investigation did not involve a study of available, affordable, accessible housing for the IDD population in New Jersey, there is no doubt that New Jersey has a housing crisis for all low-income New Jerseyans and that crisis is worse for people who need specialized housing and supports and services in the community that complement housing, especially people who have complex support needs. [190]

From all corners of our investigation, Disability Rights NJ saw that the lack of accessible, affordable housing with necessary, individualized services and supports propels people with IDD who were living in the community into nursing homes. Through our investigation, we met with nursing home residents who had been in group homes, supported housing, and their own family housing with waiver services prior to admission to a nursing home, and we heard that previous housing was often unwilling to take people back after an acute hospitalization, a fall, or when their need for assistance with activities of living like bathing and dressing increased.

It is important that the State build out a system for people with IDD that allows them to age in place. New Jersey does not yet embrace age-friendly communities that are inclusive of people with disabilities, though we appreciate and serve on Governor Murphy's initiative establishing an Age-Friendly Communities State Advisory Council.[191] We also welcome the Governor's newest budget that includes funding dedicated to developing housing for people with IDD and mental health disabilities to facilitate nursing home transitions. [192]

One way the PASRR process fosters *Olmstead* principles is by requiring the evaluation report and determination notice to include information about alternative individualized community-based housing and service options to nursing home placement, even when they are not available.[193] The purpose of these requirements is to help states plan for the future even if the system lacks resources in the present, and to better understand housing and service gaps in the system, so that states are better able to develop and implement "a comprehensive, effectively working plan to placing" nursing home residents, including those with IDD, in the community. We did not observe any evidence in any aspect of New Jersey's PASRR process that New Jersey is using PASRR to gather data about housing or services and supports needs to inform future policy.

PERSON-CENTERED PRACTICES:

The federal CFR regulations are replete with requirements that the PASRR process be individualized, culturally and linguistically adapted to the individual, and involve the participation of the person being evaluated. [194] Through technical assistance, CMS also encourages states to grow beyond mere compliance, and one way to achieve PASRR best practices is to embrace and incorporate person-centered practices throughout the PASRR process. While there are some limited attempts for "options counseling" during the DDD process for some people (most Level II screens "STOP" after the Categorical Determinations), overall New Jersey's PASRR process does not embrace person-centeredness and so fails to be an effective tool of the State's *Olmstead* plan. The lack of a person-centered focus throughout the LTSS delivery system is discussed more thoroughly in Key Finding Three, infra.

KEY FINDING NUMBER THREE:

Throughout New Jersey, people with IDD end up living in nursing homes with little regard for, and at times, against their expressed preference for living in the community. They are not engaged in meaningful person-centered planning that allows them to make an informed choice of residential setting in violation of the law. The New Jersey Constitution guarantees the fundamental right of self-determination, which includes the decision where to live. This fundamental right – to express a preference for where one lives – is also extended to people subject to guardianship, albeit, balanced with a best interest analysis. In addition, federal law affords Medicaid Long Term Services and Supports (LTSS) recipients significant rights to engage in person-centered planning, which includes their informed choice of residential setting. A choice of one – a nursing home – is not an informed choice under the law.

Through our investigative efforts, Disability Rights NJ met with 325 people [195] with IDD living across 70 nursing homes, [196] and nearly half of those who engaged in more extended conversation told us that they did not choose to live in a nursing home, that they preferred another setting (e.g., family home, their own apartment, group home), and/or that they wanted to return to a home and community-based setting.[197] The reasons these people ended up in nursing homes were varied – they were discharged to the nursing home after an acute hospitalization and after receiving rehabilitation remained on "custodial" or long-term care status, a parent-caregiver could no longer take care of them or died, a group home refused to serve them as their care needs like bathing or dressing increased – but the sentiment expressed to us by individuals were similar:

I want to go home.
I want to live in the community.
I don't want to live in a nursing home.

THE FUNDAMENTAL RIGHT TO SELF-DETERMINATION

> All persons are by nature free and independent, and have certain natural and unalienable rights, among which are those enjoying and defending life and liberty. . .and of pursing and obtaining safety and happiness. New Jersey Constitution, Article I, 1.

The fundamental right of self-determination of all people, including people with IDD, is rooted in the New Jersey Constitution, legislative acts, administrative regulations, and judicial decisions.[198] The right to make one's own decision about where to live must always be the starting place for planning conversations with individuals with IDD who are not subject to guardianship: if a person is confronting a need to make a decision about where to live, those assisting that individual – whether supporters (e.g., family or friend) or

providers (e.g., hospital discharge planners, Medicaid Managed Care Organization (MCO) care managers, DDD Support Coordinators) – must recognize that the person with IDD is leading that decision. That is the individual's guaranteed constitutional right.

People with IDD who are subject to guardianship also retain rights with respect to self-determination and expressing a preference about where they wish to live, albeit balanced against judicial concerns for their best interests. In 1994, the New Jersey Supreme Court in *In re M.R.* held that even where a person with an IDD is subject to a general guardianship, [199] the guardian must demonstrate, by clear and convincing evidence, that the individual subject to guardianship is not capable of making the decision about where they can live.[200]

Moreover, once a judge has appointed a guardian after deciding that an individual lacks capacity to exercise their constitutional right to self-determination, the Supreme Court, as well as New Jersey's guardianship statute, embrace a "substituted judgment" test when it comes to decisions like where to live. Under the "substituted judgment" test, ". . .once competent patients who have become incompetent also can express their right to self-determination. With such patients, the question is not what a reasonable person would choose, but what choice the patient would have made if able to choose." [201]

The Court explains that courts and guardians must take into consideration the decision a person who once had capacity did or would have made prior to incapacity: "[t]he substituted-judgment and best-interest tests are not dichotomous, but represent points on a continuum of subjective and objective information leading to a reliable decision that gives as much weight as possible to the right of self-determination." [202] If the guardian cannot determine an individual's decision through substituted judgment, only then does the Court turn to the "best interest" test. [203]

THE STORY OF L.C.

L.C. is a 68-year-old woman with IDD who lived independently in an apartment in the community until she needed a medical procedure. She was hospitalized for this procedure and discharged to a nursing home, initially for rehabilitative services. Eleven years later, L.C. remained in a nursing home, despite her repeated expressed desire to move back to the community. While advocating for better treatment and services in the nursing home, Disability Rights NJ also successfully assisted L.C. in moving to a group home in the community in her desired location in the state.

THE STORY OF K.K.

K.K. is a 61-year-old woman with IDD who lived her entire life in the community with her mother. K.K. was placed in a nursing home, alongside her mother, shortly after K.K. turned 54. K.K. was placed in a nursing home because her mother, and primary caretaker, was aging and unable to continue to care for K.K. K.K's mother passed away a few years after they entered the nursing home. K.K. told us that she was unhappy there and wanted to live somewhere that she could make friends and engage with others.

THE STORY OF D.F.

D.F. is a 76-year-old woman with IDD who uses a wheelchair. She told Disability Rights NJ that prior to living at the nursing home, she enjoyed living in a group home for several years. About two years earlier, she remembered falling in the shower and that the staff had trouble picking her up. She believes this is why she ended up in a nursing home. She told us that while she likes going to therapy and doing arts and crafts, she never goes outside and would like to go back to her group home.

WHAT ARE PERSON-CENTERED PRACTICES? [204]

Traditionally, healthcare systems, generally, and Medicaid long-term services and supports delivery systems, in particular, were not set up to value and incorporate each Medicaid LTSS recipient's uniqueness: people were frequently viewed through the lens of their disability, without regard to the unique, whole person they were, and the control people should have over their own choices and lives.

Person-centered practices are the opposite of this mindset, and are rooted in two concepts:

- Person-centered thinking is a set of values, skills, and tools used in person-centered planning and in the personalization of services used by people who need supports.
- Person centered planning is a set of approaches designed to assist someone to plan their own life and supports. It is used most often to enable individuals with disabilities, or otherwise requiring support, to increase their personal self-determination and improve their own independence.[205]

The Learning Community for Person-Centered Practices correctly places the emphasis on these practices: **"For people being supported by services, it is not person-centered planning that matters as much as the pervasive presence of person-centered thinking**." More information about the Learning Community for Person-Centered Practices can be found at this link: https://tlcpcp.com/. [206]

While there are distinct perspectives partaking in the LTSS-delivery system -- the person involved in person-centered practices, state Medicaid and IDD agencies, hospitals, nursing homes, HCBS providers, family, friends, and legal guardians – it is important that person-centered thinking remains at the very center of it all. A recognition of the right of people with disabilities to exercise control and choice must be pervasive. Accordingly, an LTSS-delivery system must develop policies, practices, trainings, and education all to foster that goal of "**the pervasive presence of person-centered thinking.**"[207]

THE FEDERAL MEDICAID PERSON-CENTERED PLANNING REQUIREMENTS

The federal regulatory scheme for accessing Medicaid long-term services and support (LTSS) emphasizes person-centered practices both in the rules governing nursing homes and those governing home and community-based services delivered through Medicaid waivers.[208] While person-centered practices are evident in federal law governing long-term services and supports[209] since at least the 1987 Nursing Home Reform Act[210] including the PASRR provisions,[211] the legal right to person-centered practices and planning was most recently codified and amplified by the by the Centers for Medicare and Medicaid Services (CMS) in 2014 through the HCBS Settings Rule and again in 2016 through the revised nursing home regulations including provisions related to residents' rights and comprehensive person-centered planning.[212]

HCBS PERSON-CENTERED PLANNING RULE (2014) [213]

Individuals with IDD who receive Medicaid waiver home and community-based services and supports have a legal right to person-centered planning: "We [CMS] consider the requirements outlined [in the rule] to confer to individuals the right to a person-centered service plan, and a planning process that meets these requirements." [214]

The federal rule outlines those rights in three sections: the person-centered planning process; the resulting written service plan; and the requirements for review of the plan. While the rights-based requirements for person-centered practices is embedded throughout the rule, below are several highlighted examples: [215]

THE PERSON-CENTERED PLANNING PROCESS:

- The individual receiving Medicaid services "will lead the person-centered planning process where possible." [216] Moreover, to the extent that the person's representative has a participatory role, that role should be "as needed" and defined by the individual leading the process, absent state law to the contrary.
- The individual receiving Medicaid services must be empowered to make informed choices. This means that state Medicaid agencies or their agents (e.g., MCOs or Support Coordinators) must provide the necessary information and support to ensure that LTSS recipients direct the process to the maximum extent possible and are enabled to make informed choices and decisions. Perhaps the most important informed choice is the choice about where to live. There the HCBS rule says that the state Medicaid agency must offer informed choices regarding settings (including non-disability specific settings and options for private units in residential settings) and record the alternative home and community-based settings that were considered. [217]

THE WRITTEN SERVICE PLAN:

- The written plan must address the needs, strengths, and preferences, as well as goals and desired outcomes of the individual receiving Medicaid services. [218]
- The written plan must reflect that the setting in which individuals resides is chosen by the individual, and that setting must be integrated in and support full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and received services in the community to the same degree of access as individuals not receiving Medicaid HCBS. [219]
- The written plan must be understandable to the individual (e.g., written in plain language and in a manner that is accessible) and include the written informed consent of the individual receiving Medicaid services. [220]

REVIEW OF THE PERSON-CENTERED PLAN

- The service plan must be reviewed at least every 12 months, when the individual's circumstances or needs change significantly, or at the request of the individual. *Note: CMS was particularly explicit about the right of the individual receiving Medicaid services to request a revision of the service plan.* [221]

While the 2014 Medicaid HCBS rule took a large step forward by securing a legal right to person-centered planning, and in particular for individuals with guardians, the rule reflects the tension between autonomous self-determination and risk to health and safety. [222] For example, the rule includes a provision for including risk factors and back-up measures in plans only where those strategies are needed. [223]

Through the federal comments to this rule, concerns were raised that in taking care to protect freedoms, the regulations did not provide enough to ensure reduction of risk, particularly for Medicaid recipients with diminished capacity: to that concern, CMS answered "we conclude that additional language is needed to ensure that reducing risk for individuals receiving Medicaid HCBS does not involve abridgment of their independence, freedom, and choice either generally or at the spontaneous decision of persons providing services and supports." [224] In response to these comments, CMS changed the regulations to include language that any modification had to be supported by a specific assessed need and justified in the person-centered service plan. [225]

Disability Rights NJ remains concerned that in the person-centered planning process, especially where a legal representative may seek to lead the process, the concern for "reducing risk" can quickly turn into paternalism that supersedes person-centered thinking. Ideally, stronger federal language could be implemented to ensure individuals' independence, freedom, and choice remain at the center of all plans for all Medicaid waiver participants.

NURSING HOME PERSON-CENTERED PROCESSES

In 2016, CMS issued updated federal nursing home regulations, the first comprehensive revisions since they were issued in 1991. [226] Significant in many ways, these revisions which were adopted and implemented between 2016 and 2018 and, generally, apply to all residents of nursing homes that participate in Medicare and/or Medicaid regardless of the payment source of the resident.

The focus here is on how the updated nursing home regulations enhance residents' rights to person-centered planning and the fundamental starting place are those rights contained in the "resident rights" rule, which states that the resident has: [227]

- The right to a dignified existence, self-determination, and communication with people inside and outside the nursing home. [228]
- The right to participate in the development and implementation of their person-centered plan of care, including the right to say who is included in the process, the right to request meetings, and the right to request revisions to the person-centered plan. [229]
- The right to participate in establishing goals and outcomes. [230]
- The right to self-determination which the facility must promote and facilitate through support of resident choice. [231]

Note: These rights are not circumvented by a legal guardian. [232]

Through the lens of person-centered planning in a nursing home, the most significant 2016 change to the federal nursing home regulations was the new right to comprehensive person-centered care planning. [233] The rule requires, to the extent practicable, the participation of the resident and the resident's representative and in consultation with the resident develop goals for admissions, desired outcomes, and the resident's discharge goals.

2016 KEY CHANGES: FEDERAL NURSING HOME REGULATIONS RELATED TO SELF-DETERMINATION AND PERSON-CENTERED PLANNING

Definitions [234]

- Added definition of person-centered care: for purposes of this subpart, person-centered care means to focus on the resident as the locus of control and support the resident in making their own choices and having control over their daily lives.

Residents' Rights [235]

- Self-determination moved from quality of life to resident rights.
- For residents who are not subject to guardianship, new section says that resident retains right to exercise rights not delegated to resident representative, and representative can only exercise rights specifically delegated to them by resident.
- Added protections for residents with guardians: For residents subject to guardianship, court-appointed guardian can only exercise rights given by court and resident retains right to make decisions outside guardian's authority; Guardian must consider resident's wishes and preferences; Resident must be given opportunity to participate in care planning process.
- Planning and implementing care expands resident involvement in and control over care planning, including right to identify individuals and roles to be included in planning process and participate in establishing goals, outcomes of care, request meetings and more.
- Added affirmative duty to support resident in planning process by facilitated inclusion of resident and/or representative; include assessment of resident's strengths and needs and integrate resident's personal and cultural preferences in developing care goals.
- Added protections for self-determination: A facility must promote must promote and facilitate resident self-determination through support of resident choice.

Comprehensive Person-Centered Care Planning [236]

- Care planning was previously under Resident Assessment and, now, it is its own section. The new section also contains new, strong person-centered rights.
- The care plan must include any specialized services or specialized rehabilitative services facility will provide as a result of the PASRR process.
- In consultation with resident and representative, the care plan must describe goals for admission and desired outcomes, preference and potential for discharge (facility must document if resident wishes to return to community and any referral it has made to the local contact agency) and discharge plans.

DISABILITY RIGHTS NJ ANALYSIS: FINDING THREE

New Jersey's LTSS delivery systems, particularly nursing homes, lack an ethos of pervasive person-centered thinking. While person-centered planning principles are evident in HCBS waivers, the failure to incorporate these principles into the PASRR process undermine these rights for people with IDD, even those coming from HCBS settings, when they are at risk of nursing home admission. Ultimately, the constitutional right to self-determination with respect to expressing a preference about where one lives is not a reality for most people facing nursing home admission, and certainly not for people with IDD.

NURSING HOMES

New Jersey must amend our statute and regulations, discussed below, to align with federal law and person-centered practices to force the institutional, hospital-like culture found in most New Jersey nursing homes to radically change. Through this investigation, our investigation at Woodlands and our regular nursing home monitoring, Disability Rights NJ finds that at most nursing homes we visit rights-based, person-centered thinking and practices are completely absent: residents have little to no choice in any of their day-to-day decisions from when to wake up, to food choices, to roommates, to whether they are there at all. Many units we visited are locked such that people in that unit cannot make the simple decision to walk to a different area of the nursing home, let alone go outside.[237] These practices effect all residents including those with IDD. We regularly found that nursing homes do not adhere to current New Jersey law, which is flawed, regarding rights-based person-centered practices, let alone the federal law discussed above. This must change.

Nearly fifty years ago, New Jersey progressively led the country in recognizing the need for a rights-based framework for empowering and protecting nursing home residents with the enactment of the Nursing Home Responsibilities and Residents Rights Act in 1976.[238] Resident rights regulations were also adopted under this statute.[239] For example, nursing homes are responsible for ensuring that nursing home residents have access to the New Jersey Long-Term Care Ombudsman, legal services programs, and Disability Rights NJ, the designated Protection and Advocacy.[240] The statute and regulations also enumerate the rights of residents including the right to privacy, the right to visitation, and right not to be deprived of any constitutional, civil, or legal right.[241]

However, to a significant degree, New Jersey law has not kept up with changes to federal law, and the New Jersey law now urgently needs to be amended to ensure that nursing home residents, including those with IDD, are afforded the full measure of their federal rights. Examples include:

- The right to a person-centered plan of care including specialized services;[242]
- The explicit federal right to self-determination, even for residents with guardians;[243]
- The fullness of the right to visitation; New Jersey law unduly limits visitation to "reasonable hours;"[244]
- Federally permissible reasons for involuntary discharge/transfer reasons, as well as requirements for written notice and appeal rights under 42 CFR §431 Subpart E;[245]
- Prohibitions on 3rd party guarantor agreements;[246]
- Discharge planning rights[247]

In the absence of voluntary compliance with the law, right-based violations can also be enforced through the courts. One of the greatest strengths of the New Jersey Nursing Home Responsibilities and Residents Rights Act in 1976 is that it includes a private right of action, including actual and punitive damages, attorney fees and costs, and even treble damages in certain circumstances.[248] Though little used, this right of private action holds the potential to make change, especially if the New Jersey statute and regulations were amended to include the fullness of the federal rights.

The Department of Health's (DOH) inspection and survey process is another way the State can ensure that nursing homes are not violating residents' rights including those that ensure a person-centered process. [249] A review of CMS 2022 data regarding resident rights citations by state survey agencies rank New Jersey's as the 48th worst in comparison with other states and the District of Columbia. This means DOH surveyors cite New Jersey nursing homes for resident rights citations less frequently than 47 other states and DC. Only New York, Alabama, and Kentucky perform worse on this measure than New Jersey.[250] New Jersey must do better.

The widespread dysfunction in the nursing home industry is beyond the scope of Disability Rights NJ's investigation with respect to residents with IDD. No doubt we saw it throughout our work here, at Woodlands, and through our regular monitoring. We include several examples throughout this report. A comprehensive review of New Jersey's nursing homes and recommendations are forthcoming through the work of the New Jersey Task Force on Long-Term Care Quality and Safety, of which we were a statutory member.

PERSON-CENTERED PLANNING AND SELF-DETERMINATION IN NEW JERSEY'S WAIVER PROGRAMS

Disability Rights NJ found that there is a long history of efforts by the state Medicaid agency and DDD to develop and implement robust person-centered planning practices in HCBS waivers, especially through the Medicaid waivers designed to support people with IDD.[251] However, we also found that New Jersey is simply not there yet – person-centered thinking that recognizes the constitutional right to self-determination and the person-centered rights enumerated in the 2014 HCBS rule is not pervasive throughout the system. We found examples of where the State regulations and process related to Medicaid waivers is not as strong as the the federal rule.[252] In addition, the failure to incorporated person-centered practices required by the federal PASRR law directly impacts continuity of care between HCBS and nursing home settings, effectively denying people with IDD on HCBS waivers access to those protections at the exact moment they need them most, when at risk of nursing home placement.

§ 1115 WAIVER

New Jersey delivers LTSS waiver services through an §1115 Demonstration waiver[253] called the New Jersey FamilyCare Comprehensive Demonstration[254] (Demonstration Waiver). The Demonstration Waiver, originally approved in 2012, now incorporates five previously approved §1915(c) HCBS waivers (e.g., Global Options, Community Resources for People with Disabilities, Traumatic Brain Injury waiver, HIV/AIDS waiver, and DDD Community Care Waiver) and added the DDD Supports Program for individuals with IDD who do not

necessarily meet a clinical criteria of an institutional level care in 2012.

Throughout the Demonstration Waiver, CMS requires that New Jersey engage in person-centered practices and planning. For example, in the "plan of care" requirements, the Wavier requires the State to ensure the individuals will lead the person-centered planning process and that the process will be highly individualized with a focus on the person's abilities and preferences.[255] An innovative requirement under the Demonstration Waiver is the requirement that the person-centered plan include housing supports through housing transition navigation services led by MCOs.[256]

Home and community-based services are provided to adults with IDD through three primary waivers, though limited HCBS services (e.g., Personal Care Assistance and Adult Medical Day) can be accessed through Plan A – State Plan services for all Medicaid recipients:[257]

- Managed Long Term Services and Supports Program (MLTSS): MLTSS provides both nursing home and HCBS services to people who meet a "nursing facility level of care." Both State Plan services (e.g., Personal Care Assistance or PCA) and waiver services (e.g., home modifications) are delivered through managed care. An individual with IDD may choose to be on only one waiver, so if they opt for MLTSS they will not receive services from DDD. Private duty nursing (PDN) is an MLTSS waiver service.[258]
- DDD Supports Program (with Private Duty Nursing accessed through MLTSS): The DDD Supports Program provides State Plan Services (e.g., PCA) delivered through managed care as well as DDwaiver services (e.g., support coordination and direct service professionals) which are delivered through fee-for-service based on a person's tier/budget. Individuals with IDD on this waiver do not need to meet an institutional level of care. PDN service is available, and is delivered through the managed care.[259]
- Community Care Program: The CCP provides an array of services, including group homes, to individuals who meet an institutional ICF-IDD level of care. Waiver services are based on an individual's tier/budget and are delivered through fee-for-service. State Plan services (e.g., PCA if someone is living in their own home, not a group home) are delivered through managed care.[260]

DDD PERSON-CENTEREDNESS PRACTICES:

Disability Rights NJ found that the regulations governing DDD group homes (and other HCBS waiver settings) do not comply with the person-centered planning rights afforded to all HCBS wavier participants in the federal HCBS Settings Rule that have been operative since 2014. For example, in 2022, when the Department of Human Services proposed amendments to the regulations governing group homes for people with IDD, purportedly to come into compliance with the federal HCBS Settings Rule, Disability Rights NJ submitted this comment: "we recommend that the term 'person-centered planning process' be defined consistent with the federal person-centered planning rule, 42 CFR § 441. 301(c)(1), (2), and (3). [261]

A copy of DRNJ's comments on this proposed regulation can be found here: https://disabilityrightsnj.org/wp-content/uploads/220930-Disability-Rights-NJ-Comments-to-Proposed-Rules-Regarding-HCBS-in-Assisted-Living.docx

The State responded, showing that it either does not understand or it intentionally ignored the richness of the federal law:

> RESPONSE: "Person-centered planning," as defined in the regulation, means a process of helping individuals, in accordance with their needs and preferences, to achieve a lifestyle that is consistent with the norms and patterns of general society and in ways that incorporate the principles of age appropriateness and least restrictive interventions. The Department finds that this definition is sufficient. The person-centered planning process utilized in New Jersey is robust and consistent with 42 CFR 441.301(c)(1), (2), and (3). It is defined in various sections of the Division's Community Care Program Manual and Supports Program Manual, particularly at sections 6 - Care Management, 7 - Service Plan, and 17.18 - Support Coordination. These sections require conflict-free care management; state that the individual is at the center of the process; contain operating principles; discuss planning team membership and resolving differences of opinion among planning team members; and include the definition of support coordination service.[262]

To be clear, person-centered planning is not "helping individuals" (which is the essence of paternalism); it is empowering them to lead the process, providing supports to ensure that they direct the planning to the maximum extent possible. When given the chance, the State failed to take the legally required and right path.

Despite this grave lapse in the regulations, DDD does include person-centered process through the two waivers it administers:

DDD "is committed to opportunities for individuals with intellectual and developmental disabilities to make individualized, informed choices and self-direct their services."[263] While both the DD Supports and Community Care programs incorporate person-centered practices through development of plans of care, participants can also self-direct services with the assistance of a Support Coordinator.[264] According to DDD, the Support Coordinator is responsible for ensuring the individual "is at the center of the planning process and in determining the outcomes, services, supports, etc. that he/she desires."[265]

Moreover, DDD emphasized that "[s]upport coordinators can encourage independent decision-making and self-determination for persons with IDD by fostering exposure and understanding in important life categories that may include residential, medical, educational, vocational, and legal areas."[266]

DDD mandates that Support Coordinators use of the Person-Centered Planning Tool (PCPT) and New Jersey Individualized Service Plans (ISP).[267] The Boggs Center on Developmental Disabilities in collaboration with DDD developed a comprehensive guidebook related to person-centered planning.[268] Support coordinators, in conjunction with the individual with a disability, their family, and/or support system, utilize the PCPT and ISP "to identify the support and health and safety needs, preferences, strengths, and desired outcomes of the person."[269] Ultimately, the goal is to ensure that the person with a disability is at the center of the planning process for meeting their needs and goals for the future.

Though DDD mandates the use of person-centered planning through the CCP and Supports manuals, there is still great variation among support coordinators, and the actual implementation of person-centered planning. Engaging in person-centered planning is much more than merely checking a box. All players involved (e.g., supports coordinators and family members) should bring every aspect of the planning process back to the person at the center. Rather than focusing on the needed services as the goal, the goals of the person should be at the center of the planning process and the needed services are the means to achieve that goal.

FAILURE BY STATE TO MAXIMIZE PERSON-CENTERED OPPORTUNITIES UNDER OTHER FEDERAL LAWS

Federal law envisions that the PASRR process be used by states to ensure that people with IDD and mental health disabilities live in the most appropriate, least restrictive setting with services and supports. To that purpose, PASRR can be a powerful tool in a state's *Olmstead* plan – especially when a state embraces person-centered thinking and practices throughout the PASRR process. New Jersey's PASRR process is not person-centered, both in its misapplication of federal law (e.g., unlawful definition of specialized services) and overarching implementation. Correction of the CRF compliance issues raised herein also creates an opportunity to incorporate pervasive person-centered design into New Jersey's process.

New Jersey has several other federal resources available to foster culture change around person-centered thinking and self-determination in the LTSS delivery system:

- Section Q of the MDS: The Minimum Data Set (MDS) is a required quarterly assessment that nursing homes must complete for each resident. It is a powerful tool for advocates and states to identify and transition people with disabilities back into the community. Section Q of the MDS requires the nursing home to ask residents and/or their family if the resident wants to return to the community. If the resident indicates that they do want to return to the community, they should be referred referred to the local contact agency (the Office of Community Choice Options in NJ) and to the Money Follows the Person program (I Choose Home New Jersey).[270]

- MFP/I Choose Home New Jersey: Money Follows the Person (MFP) is a federal program that enables state Medicaid programs to help Medicaid beneficiaries living in institutions (like nursing homes) transition back to the community. In New Jersey, MFP is branded as I Choose Home New Jersey. New Jersey can better use referrals to I Choose Home New Jersey as another tool to identify individuals with IDD in nursing homes and facilitate a return to the community for those individuals. The data above, provided to Disability Rights NJ by the I Choose Home program, demonstrates the success of the program especially for other adults and people with physical disabilities.[271]

DDD has had great success using MFP moving people with IDD from state Developmental Centers to home and community-based settings, and should use those lessons learned couple with the expertise of the MFP/I Choose Home program to focus on transition opportunities for people with IDD living in nursing homes.

MFP TRANSITIONS		
Population	**Total Transitions 7/1/08 to 8/31/23**	**Year to Date 1/1/23 - 8/31/23**
Older Adults	1594	123
Individuals with Physical Disabilities	1564	106
Individuals with Intellectual Disabilities/Developmental Disabilities	974	12
Total	4132	241

HOUSING AS A BARRIER

The right to self-determination or the choice of where someone lives is guaranteed by the New Jersey Constitution, the Americans with Disabilities Act, *Olmstead v. L.C.*, and federal and state person-centered planning rules. People with IDD cannot enjoy the fullness of this constitutional right because New Jersey does not have sufficient accessible,[272] affordable community-based housing period. The the problem is exacerbated for people with disabilities, especially people with IDD who have more complex support needs (e.g., individuals with dual diagnosis, significant medical needs, and even people who need help with activities of daily living or ADLs, like bathing, dressing, and ambulation).

While there will always be more to do, Disability Rights NJ recognizes and appreciates several innovative efforts by the State to target and expand affordable, accessible housing for at-risk people, especially those with IDD who are institutionalized or at risk of institutionalization in nursing homes:

- **Medicaid Healthy Homes:** In July 2021, as part of New Jersey's Medicaid HCBS Spend Plan under the American Rescue Plan, the state Medicaid agency (DMAHS) requested CMS approval for the development of 100 deed-restricted, subsidized, and accessible rental units for Medicaid recipients at risk of homelessness or institutionalization. On February 1, 2023, DMAHS most recently updated the status of Healthy Homes implementation, stating that working with the Department of Community Affairs, a kickoff will occur in 2023.[273]

- **State Budget 2024**: In his 2024 proposed budget, Governor Murphy include money to support individuals with IDD transitioning out of nursing homes back to the community. The 2024 budget as adopted by the NJ Legislature includes funds to support the development of 25 group homes with 100 residential beds to support people with IDD moving out of nursing homes and other institutional settings. In addition, there is funding to support nursing facility transitions for individuals with mental health disabilities. [274]

Disability Rights NJ saw the importance of having an already existing supply of housing available for nursing home transitions through our investigation at Woodlands. Nearly all residents were transferred to other nursing homes rather than HCBS settings, simply because there were no choices in the community. The ability of a person with IDD to decide where they want to live and to pick their setting of choice requires a robust, available housing stock. New Jersey's innovative efforts in Medicaid Healthy Homes and the dedication of funds to increase nursing home transitions in the 2024 budget are positive steps to ensure that people with IDD can fully engage in their legal right to self-determination with respect to their informed choice of residential setting.

RECOMMENDATIONS AND CONCLUSIONS

Below Disability Rights NJ presents our recommendations for moving New Jersey from a state that over-relies on institutional nursing homes for people with intellectual and developmental disabilities (IDD) to one that embraces and makes real an individualized, person-centered long-term services and supports (LTSS) system that prioritizes high-quality, robust home and community-based housing, services, and supports.

While our investigation of nursing homes focused on people with IDD, many of our findings and recommendations apply to all people residing in nursing homes regardless of age or disability. The truth is that for all current and future nursing home residents, the State must have the courage to radically change the nursing home industry in New Jersey. *See*, Charles Sabatino, *Why Nursing Homes Need a Total Redesign,* HEALTH AFFAIRS FOREFRONT (April 3, 2023), https://www.healthaffairs.org/content/forefront/why-nursing-homes-need-total-redesign.

Summary of Key Finding One: The State of New Jersey has failed to collect and maintain complete, consistent, and accurate data related to individuals with IDD living in nursing homes in New Jersey and appears to be substantially undercounting the number of nursing home residents with IDD.

A. New Jersey should develop a cross-agency, centralized data storage system that collects and maintains complete, consistent, and accurate data related to people with IDD (and mental health disabilities) living in nursing homes. Data should be collected from all available sources, including Centers for Medicare and Medicaid Services (CMS) nursing home survey reports, including Preadmission Screening and Resident Review (PASRR) data; MDS 3.0 Frequency Reports, including PASRR data; relevant information from New Jersey's Money Follows the Person (MFP) program (branded "I Choose Home"), MDS 3.0 Section Q referrals to the Local Contact Agency; Medicaid claims, DDD, MCOs, and other information derived directly from nursing homes.

i. This database should be used to inform the development of the State's nursing home *Olmstead* plan; and the information should be used by the I Choose Home (aka MFP), DDD Support Coordinators, and MCOs should reach out to nursing home residents with IDD to identify people who want to transition to a less restrictive HCBS setting appropriate to their needs.

B. New Jersey should collect and/or aggregate existing data related to demographic information (e.g., age, race, ethnicity, disability, language spoken, sexual orientation, or gender identity) that would aid in examining implicit bias in the long-term care services and supports delivery system and assist state policy makers as they build out future opportunities to advance equity in home and community-based settings. See, Amber Christ and Valencia Sherman-Greenup, Building an Equitable Medicaid HCBS Infrastructure in NJ for Older Adults, Justice in Aging (June 2022), https://justiceinaging.org/wp-content/uploads/2022/06/Building-an-Equitable-Medicaid-HCBS-Infrastructure-in-NJ-for-Older-Adults.pdf; MLTSS Institute, Advancing Equity Through MLTSS Programs, Advancing States (February 2023), http://www.advancingstates.org/sites/nasuad/files/Advancing%20Equity%20MLTSS%20Feb.%2023.pdf.

C. New Jersey should maintain and publish a public dashboard that includes aggregate, non-personally identifiable information about individuals in nursing homes with disabilities including IDD and mental health disabilities, akin to the Department of Human Services NJFamilyCare dashboards, see Long Term Care: Month at a Glance, https://njfamilycare.dhs.state.nj.us/analytics/home.html (accessed September 5, 2023. The dashboards should, at a minimum, provide information by age-groups, county, MCO enrollment, and dual status (i.e. Medicare and Medicaid).

D. New Jersey should adopt and implement PASRR quality monitoring and quality improvement (QM/QI) indicators, critical for measuring and promoting the success of the State's PASRR program, using CMS's model list of QM/QI measures with technical assistance from the PASRR Technical Assistance Center (PTAC). While states can develop their own indicators, the CMS model indicators (e.g., % of Level I evaluations done before admission; # of nursing facilities (NF) admissions under Exempted Hospital Discharges; # of positive determinations that recommend specialized services) have been identified as providing data that would likely support a state's PASRR activities. See, PASRR Technical Assistance Center, 2019 PASRR National Report (December 2019), https://www.medicaid.gov/sites/default/files/2020-02/2019-pasrr-national-report.pdf. Model QI/QM indicators could help the State identify the number of people with IDD and mental health disabilities seeking admission to and admitted to nursing homes, as well as ensure that Exempted Hospital Discharges were not overused, that time-limited PASRR Categorical Determinations were revisited in a timely manner, and that people were appropriately screened for specialized services, among other quality-control uses.

E. New Jersey should analyze MDS 3.0 data related to PASRR before and directly after COVID-19 hit the State's nursing homes in 2020 to determine if it is accurate that nearly 20% of the people with IDD were no longer living in nursing homes from March 2020 to June 2020, and if accurate, undertake a study to determine

what happened to those people – did they move to their own homes or community-settings; did they die, and if so, of COVID-19; or is there another explanation? This analysis is important to better understand the risk of congregate living for people with IDD during wide-spread outbreaks of infectious disease. The CMS MDS 3.0 Frequency Report can be found at: https://data.cms.gov/quality-of-care/minimum-data-set-frequency.

Summary of Key Finding Two: New Jersey's PASRR regulations and practices do not align with federal law and CMS technical assistance leading to the inappropriate and potentially unlawful institutionalization of individuals with IDD in nursing homes and denial of specialized services in nursing homes where appropriate.

A. New Jersey should undertake a thorough review of the State's current PASRR process for people with IDD and mental health disabilities considering current federal requirements and technical assistance available through PTAC. (PASRR Technical Assistance Center, https://www.pasrrassist.org/.) To the extent that the State has already engaged with PTAC, key stakeholders should be part of the discussions, see B.

B. Key stakeholders, including people with IDD, their families and supports, and advocates must be full participants in the review of the current PASRR process and any proposed revision to State PASRR regulations or the sub-regulatory process.

C. New Jersey should amend and/or adopt relevant statutes and regulations as part of its plan to redesign and implement a PASRR system that both complies with CFR regulations and is a powerful tool of the State's comprehensive nursing home *Olmstead* plan. This may require action by the New Jersey Legislature, the Department of Human Services, and the Department of Health.

   i. The 1988 statute and related regulations pertaining to "preadmission screening" (PAS), generally used to ensure that Medicaid recipients meet a nursing facility level of care as a condition of federal reimbursement, should be reviewed and amended to minimize confusion with the PASRR process.

D. New Jersey should keep principles of person-centered thinking at the forefront of the redesign of the State's PASRR process and, with deliberation and intention, incorporate person-centered processes into all aspects of the PASRR process. To achieve pervasive person-centered thinking in New Jersey's system, ongoing input from key stakeholders, especially people with IDD and mental health disabilities, will be essential. See, PASRR Technical Assistance Center, PASRR Assessors and Evaluators: The Importance of a Person-Centered Perspective, (February 15, 2022), https://www.pasrrassist.org/webinars/PASRR-Assessors-and-Evaluators%3A-The-Importance-of-a-Person-Centered-Perspective.

   i. The primary purpose of a redesigned New Jersey PASRR process must be to fully involve the people with IDD or mental health

disability in the process and to make robust, person-centered recommendations which include appropriate HCBS settings, services and supports, even if those options are not currently available. The Level II process should include face-to-face meetings that are adapted to the person's culture and language; and there must be on-going training for evaluators on person-centered practices including the rights of people with disabilities to choose where they want to live.

ii. The PASRR process should not operate as a rubber stamp, using optional exclusions to approve predetermined admissions to nursing homes. To that end, New Jersey should reconsider its decision to opt into Exempted Hospital Discharges and Categorical Determinations which are not individualized and have the potential to evade the full Level II Evaluation and Determination process.

E. As part of this wholesale redesign of New Jersey's PASRR system and the definition of "specialized services":

i. New Jersey should amend the definition of specialized services to align with the federal requirements such that specialized services are those services delivered to nursing home residents with IDD or MI, both in the nursing home and in community-settings with a primary purpose to help people transition to HCBS settings; definitions must be changed to remove requirements that specialized services are provided in ICF-IDDs (i.e. Developmental Centers) or in-patient psychiatric hospitals.

ii. State nursing home regulations should be amended to explicitly incorporate the 2016 changes to the federal regulations, including those related to comprehensive person-centered plans of care and the inclusion of specialized services and specialized rehabilitation services in those plans.

iii. The state Medicaid agency (DMAHS) should seek State Plan Amendments (SPAs) from CMS for specialized services, including waiver-like specialized services designed to promote continuity of care between HCBS settings and nursing homes with the goal of promoting nursing home diversion and transition. See, PASRR Technical Assistance Center, Slides, Good Practices for Adopting Waiver Services in the Nursing Home Benefit: A Specialized Services State Plan Amendment (November 10, 2020), https://www.pasrrassist.org/_files/ugd/85e9d6_1bf91d9c2da64f0db938cbb8ee808344.pdf

iv. PASRR Level I, Level II, and Resident Review forms should be revised to align with the redesigned PASRR process.

F. As part of the implementation of a new PASRR system, New Jersey should engage in comprehensive outreach and training to all participants in the system: DHS staff from the state Medicaid agency (DMAHS); the Office of Community Choice Options (OCCO); the Division of Developmental

Disabilities (DDD); the Division of Mental Health and Addiction Services (DMHAS); DOH's Division of Behavioral Health Services and key state psychiatric hospital personnel; the Offices of Long-Term Care Resiliency and Health Systems; the NJ Office of the Public Guardian and the Bureau of Guardianship Services; DDD Support Coordination providers; mental health providers; Managed Care Organizations (MCOs); hospitals (especially discharge planners); and nursing homes. As part of this outreach and training, New Jersey should call on the expertise of Disability Rights NJ as the designated P&A, the Boggs Center on Developmental Disabilities, the New Jersey Council on Developmental Disabilities, the Ombudsman for Individuals with IDD and Their Families, and the New Jersey LTC Ombudsman.

Summary of Key Finding Three: Throughout New Jersey, people with IDD end up living in nursing homes with little regard for, and at times, against their expressed preference for living in the community. The New Jersey Constitution and federal person-centered planning laws guarantee the right to express a preference for where one lives and to lead the person-centered planning process. People receiving LTSS, including those with IDD, are frequently denied the fullness of these rights.

A. New Jersey should review person-centered rights and practices throughout the LTSS delivery system, including nursing home practices, MLTSS and DDD-administered waivers, to ensure compliance with the constitutional right to self-determination, federal law, and pervasive person-centered thinking. Key stakeholders should be a part of these discussions. See, N. Isvan, A. Bonardi, D. Hiersteiner, Effects of person-centered planning and practices on the health and well-being of adults with intellectual and developmental disabilities: a multilevel analysis of linked administrative and survey data, Journal of Intellectual Disability Research (February 20, 2023)), https://doi.org/10.1111/jir.13015; The National Center on Advancing Person-Centered Practices and Systems, https://ncapps.acl.gov/ (accessed September 5, 2023).

B. In line with revisiting all person-centered practices, New Jersey should review and revise service plans and planning processes across the LTSS system consistent with federal requirements for person-centered practices: nursing home interdisciplinary care plans, MLTSS Plans of Care, and DDD-administered waiver Individualized Service Plans (ISPs). For example, the federal HCBS rule requires that a robust person-centered written service plan include goals and outcomes that are not defined exclusively by covered Medicaid services and for the planning process to yield innovative ways to meet the broader goals and desired outcomes of Medicaid recipients. Service plans should not be a mere recitation of Medicaid-approved services that address need for assistance with ADLs and IADLs (e.g., bathing, toileting, meal preparation). See, Gwen Orlowski and Julie Carter, A Right to Person-Centered Planning, Justice In Aging (April 2015), http://justiceinaging.org/wp-content/uploads/2015/04/FINAL_Person-Centered_Apr2015.pdf.

C. For people in nursing homes with IDD coming from DDD-administered waiver programs who intend to return to their home in the community, New Jersey should review practices related to moving people with IDD from the Supports or Community Care Program to MLTSS prematurely. At the very least, DDD clients should generally remain on DDD waivers for the full 180 days currently approved by CMS. In addition, the State should continue to seek CMS-approval for a Demonstration Waiver provision that allows enrollment in a DDD-administered waiver for up to 360 days rather than 180 days. DDD clients in nursing homes should maintain their pre-institutionalization Support Coordinator during this time, ideally for all 180 days, and Support Coordinators should have additional specialized training in nursing home diversion and transition. For longer term nursing home residents, including those with IDD on MLTSS, the State should substantially reduce the ratios for nursing home MCO care managers (currently 1:240) and provide additional specialized training in nursing home transition to them. Support Coordinators and MLTSS care managers should be trained to identify and refer residents with IDD who are interested in transitioning to the community to I Choose Home NJ (MFP) and should educate residents and families on Section Q of MDS 3.0 as a tool for transition.

D. In order to address the lack of capacity in the community, DDD should dedicate a team of staff to work with Support Coordinators and individuals with IDD residing in nursing homes to develop discharge and transition plans that will assist any individual that chooses to move to a community-setting and work to facilitate discharge from the nursing home in a timely manner.

E. New Jersey should add a consumer education and training waiver service to MLTSS, DD Supports, and the Community Care Program, which would be designed to provide a rights-based framework, help develop self-advocacy skills including skills needed to exercise informed choice, and control and responsibility over waiver supports and services. See, Gwen Orlowski and Julie Carter, A Right to Person-Centered Planning, Justice In Aging (April 2015),https://www.dhs.wisconsin.gov/familycare/mcos/fc-fcp-2022-generic-final.pdf for a discussion of Wisconsin's person-centered care planning services.

OTHER RECOMMENDATIONS:

A. In addition to ensuring that New Jersey regulations include all the person-centered protections of the federal nursing home and HCBS regulations, New Jersey should review and amend all state regulations related to nursing homes to comply with the fullness of the 2016 federal CFR regulatory changes. For example, New Jersey regulations need to be changed to align with the involuntary discharge and involuntary transfer provisions, including written notice and appeal rights, visitation, and provisions related to persons subject to guardianship.

B. The lack of available, affordable, accessible housing permeates all aspects of New Jersey's over-reliance on institutional nursing homes for all residents, including those with IDD and mental health disabilities. Under the Supreme Court's Olmstead decision, the state must develop

and implement a "comprehensive, effectively working plan for placing" nursing home residents with disabilities, including people with IDD, in community-based programs. This requires significantly more housing options with individualized, person-centered services and supports that can meet the needs of all people, including those with more complex support needs. A comprehensive *Olmstead* plan to divert and transition older adults and people with disabilities from nursing homes requires the input and buy-in from the Department of Human Services, the Department of Health, and the Department of Community Affairs.

C. As part of developing and maintaining available, affordable, accessible housing, New Jersey should revisit recently adopted regulations meant to comply with the settings portion of the federal 2014 HCBS Rule that went into effect in March 2023. As Disability Rights NJ commented as part of the regulatory process, the rules, as proposed and adopted, violate aspects of the federal law and, in particular, do not provide HCBS tenants protection from unlawful eviction under or comparable to New Jersey's Anti-Eviction Act. For example, the rules as adopted potentially allow group home providers to refuse to have a resident return to a group home after a hospitalization.This would be unlawful in a typical apartment under New Jersey law as well as a nursing home under federal law. New Jersey should consider adding a short-term post-hospitalization waiver benefit in HCBS settings to allow for additional services for a period of time. *See,* https://disabilityrightsnj.org/whats-happening-now/person-first-nursing-homes-report/

D. New Jersey should follow the lead of other states and advocates and better leverage Section Q of the MDS 3.0 as a tool for community transition referrals by using "Q+ factors" developed by researchers. See, Brant E. Fries and Mary L. James, Beyond section Q: prioritizing nursing home residents for transition to the community. 12 BMC Health Serv Res 186 (2012), https://doi.org/10.1186/1472-6963-12-186. For example, New Jersey can follow the lead of Ohio. Their MFP program signed a data use agreement with Ohio's DOH, which collects and manages MDS, and began to identify residents using several of the Q+ factors, in addition to responses to the Section Q questions. See, Advancing States, Minimum Data Set (MDS) and Section Q for Community Transitions, 2020 Virtual Home & Community-Based Services Conference, (December 8, 2020) http://www.advancingstates.org/sites/nasuad/files/u24453/MDS%20Section%20Q%20and%20Community%20Transitions%20%20Master%20Deck%20%5BAutosaved%5D.pdf, at 16.

E. New Jersey should ensure that federal person-centered principles regarding hospital discharges are included in state regulations. See, 42 C.F.R. § 482.43: The hospital must have an effective discharge planning process that focuses on the patient's goals and treatment preferences and includes the patient and their caregivers/support person(s) as active partners in the discharge planning for post-discharge care. The discharge planning process and the discharge plan must be consistent with the patient's goals for care and their treatment preferences, ensure an effective transition of the patient from hospital to post-discharge care, and reduce the factors leading to preventable hospital readmissions.

F. The Department of Health should hire sufficient Survey staff and provide in-depth training to Surveyors on PASRR, Residents Rights, and person-centered care planning to better identify and cite these violations. Survey staff should have a baseline understanding of the State's *Olmstead* plan for nursing home residents and have high functioning referral processes with other state agencies (e.g., LTC Ombudsman's I Choose Home program).

In conclusion, Disability Rights NJ implores the State to abide by its *Olmstead* obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs. To accomplish this goal, the State must utilize data, update statutes and regulations, and develop housing, services, and supports all to meet the needs of individuals with IDD in the way in which they are entitled: person-first.

ENDNOTES

INTRODUCTION AND EXECUTIVE SUMMARY ENDNOTES

1. In this report, Disability Rights NJ will use the term "nursing home" throughout to refer facilities licensed under N.J.S. § 26:2H-29 et seq., N.J.S. § 26:2H-47 et seq., and N.J.A.C. § 8:39–1.1 et seq. Nursing homes may also participate with Medicare and/or Medicaid. (N.J.A.C. § 8:85-1.3). Medicare-participating facilities are certified as "skilled nursing facilities"(42 U.S.C. § 1395i-3(a)) and Medicaid-participating are certified as "nursing facilities" (42 U.S.C. § 1396r(a)); facilities can be both Medicare- and Medicaid-certified.

   Some nursing homes in NJ as have a special license to operate in whole or in part as a "special care nursing facility" (SCNF) (N.J.A.C. § 8:85-2.21); per NJ regulations, those special care categories are ventilator/respirator, TBI/coma, pediatric, HIV, neurologically impaired, and behavioral management. N.J.A.C. § 8:85-3.15(a)(2). Special care nursing facilities are eligible for a higher reimbursement rate. N.J.A.C. § 8:85-3.15(a).

   For more information about the number of COVID-19-relates deaths in New Jersey, please visit: https://covid19.nj.gov/forms/datadashboard

2. In this report, Disability Rights NJ uses the term "IDD" to refer to individuals with intellectual and developmental disabilities. The current federal Preadmission Screening and Resident Review (PASRR) regulations [defined elsewhere in this report] use the term "IID" to refer to people with intellectual disabilities or related conditions. 42 C.F.R. § 483.102(b)(3) (defining intellectual disability as including related conditions as defined by 42 C.F.R. § 435.1010.) In the 2020 proposed regulations, CMS proposed to revise the definition of intellectual disability and change the abbreviation for intellectual disability to "ID." Although the proposed regs were never promulgated, as noted [elsewhere within this document], the PASRR Technical Assistance Center run by CMS uses the term "ID" throughout its materials.

3. *Olmstead v. L.C.*, 527 U.S. 581 (1999) was the landmark case which recognized the right of individuals with disabilities to live in community settings. In 1995, Lois Curtis, a woman with intellectual disabilities and a diagnosis of schizophrenia, contacted the Atlanta Legal Aid Society while she was institutionalized in Georgia Regional Hospital. Atlanta Legal Society, *Olmstead v. L.C.*: History and Current Status, https://www.olmsteadrights.org/about-olmstead/.

   Curtis filed suit against Georgia state officials under 42 U.S.C. § 1983 and Title II of the Americans with Disabilities Act, alleging that the state's failure to place her in a community-based program once such placement had been determined to be appropriate constituted unlawful discrimination on the basis of disability. *Olmstead* at 581. Elaine Wilson, a woman with intellectual disabilities and a diagnosis of a personality disorder, soon joined the suit with an identical claim. Atlanta Legal Society, *Olmstead v. L.C.*: History and Current Status, https://www.olmsteadrights.org/about-olmstead/.

   Both the District Court and Appeals Court rejected the State's defense that its failure to place Curtis and Wilson in an appropriate community placement due to alleged "inadequate funding" did not constitute discrimination under the ADA, and the State appealed. A plurality of the Supreme Court affirmed the 11th Circuit in substantial part. Deciding the case on statutory grounds, the plurality held that "unjustified isolation…is properly regarded as discrimination." *Olmstead* at 597. The plurality also held that the 11th Circuit's instruction on the State's fundamental alteration defense was too restricted, holding that "in evaluating a State's fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably." *Olmstead* at 597.

Justice Ginsburg's opinion for the plurality relied on a close reading of the Attorney General's regulation implementing the statute, which reads in relevant part: "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." *Olmstead* at 591 (quoting 28 CFR § 35.130(d) (1998)). According to the plurality, the Attorney General made two key determinations in issuing the regulation: first, that the scope of discrimination under the ADA includes "unjustified institutionalization, and second, that the obligation of the state to remediate such discrimination is limited by the fundamental alteration defense." *Olmstead* at 596-7. The plurality found that this interpretation of the ADA by the attorney general was warranted, given Congress' explicit identification of "segregation" in the preamble of the ADA. *Olmstead* at 600.

4. *Olmstead v. L.C.*, 527 U.S. 581, 592 (1999). "As Congress instructed, the Attorney General issued Title II regulations, see 28 CFR pt. 35 (1998), including one modeled on the § 504 regulation just quoted; called the 'integration regulation,' it reads: 'A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.' 28 C.F.R. § 35.130(d) (1998). The preamble to the Attorney General's Title II regulations defines 'the most integrated setting appropriate to the needs of qualified individuals with disabilities' to mean 'a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.'

5. The Preadmission Screening and Resident Review requirements (42 U.S.C. § 1396r(7); 42 C.F.R. §§ 483.100 et seq.), the HCBS Person-Centered Planning rule (42 C.F.R. § 441.301(c) (2019), MDS PASRR reporting requirements (42 C.F.R. § 483.20(e)), Section Q of the MDS (Centers for Medicaid and Medicare Services, Long-Term Care Resident Assessment Instrument User's Manual, Version 1.1.8.11, Draft Version effective October 1, 2023, available at https://www.cms.gov/files/document/draftmds-30-rai-manual-v11811october2023.pdf-0, at Q-1,) and various components of nursing home assessment and plan of care requirements.

6. Disability Rights New Jersey has authority under 42 U.S.C. § 10807 and 42 U.S.C. § 10805 of the Protection and Advocacy for Individuals with Mental Illness Act ("PAIMI Act") to provide legal representation to individuals with mental illness in systems cases. Disability Rights New Jersey has authority under 42 U.S.C. § 15043 for Protection and Advocacy for Persons with Developmental Disabilities ("PADD") to provide legal representation to individuals with developmental disabilities in systems cases.

   Intermediate care facilities for individuals with intellectual and other developmental disabilities are known in New Jersey as Developmental Centers. The Medicaid Act, 42 U.S.C.A. § 1396d(b), sets out the federal statutory authority for intermediate care facilities for individuals with developmental or intellectual disabilities. The state statutory authority for Developmental Centers is found in N.J.S.A. § 30:4-165.1-165.15. The Division of Developmental Disabilities currently operates five developmental centers across the state of New Jersey: Green Brook Regional Center in Green Brook, NJ; Hunterdon Developmental Center in Clinton, NJ; New Lisbon Developmental Center in New Lisbon, NJ; Vineland Developmental Center in Vineland, NJ; and Woodbine Developmental Center in Woodbine, NJ.

   Public Institutions for individuals with mental health disabilities ("State Psychiatric Hospitals") in New Jersey are known as State Psychiatric Hospitals. The Medicaid Act, 42 U.S.C.A. § 1395x(f) sets out the federal statutory authority for State Psychiatric Hospitals. CMS retains regulatory authority over the State Psychiatric Hospitals under 42 C.F.R. § 482. New Jersey statutory authority for the designation of New Jersey's State Hospitals comes from N.J.S.A. § 30:4-160-164. The four State Hospitals are Ancora Psychiatric Hospital, Greystone Park Psychiatric Hospital, Trenton Psychiatric Hospital, and the Ann Klein Forensic Center.

   In 2005, Disability Rights New Jersey (then called New Jersey Protection and Advocacy) filed NJP&A v. Davy, 3:05-cv-01784 (2005). Disability Rights New Jersey, along with co-counsel, asked the court to order New Jersey to allow its state hospital residents on CEPP status to receive services in the most integrated setting appropriate for their needs, to limit CEPP status to 60 days, and to require the state to provide monthly reports to Disability Rights detailing the progress of individuals on CEPP status. At the time, approximately half of all psychiatric hospital patients were on CEPP status, and many had been waiting for discharge for years. In 2009, the parties came to a settlement agreement that required New Jersey to discharge over 1,000 patients into community settings with appropriate supports and to increase community mental health services capacity across the state. The state met its obligations under the settlement by 2018.

7. In two lawsuits filed against the State of New Jersey – Disability Rights New Jersey, Harmon, Thompson, and Stevens v. Velez, No. 3:08-cv-04723 (2005) and Disability Rights New Jersey v. Velez, No. 3:05-cv-01858 (2008) – Disability Rights NJ challenged the State's practice of illegally segregating people with ID into large state-run Developmental Centers and failing to provide sufficient community-based services and supports, including affordable, accessible housing.

   The 2005 lawsuit alleged that the shortage of community services created a backlog of residents stuck in institutions who wanted to live in the community, and the 2008 lawsuit alleged that people living in family homes who needed residential services stuck on a waitlist indefinitely. Amended Complaint, Disability Rights New Jersey, Harmon, Thompson, and Stevens v. Velez, No. 3:08-cv-04723 (Feb. 1, 2007) ECF No. 17; Complaint, Disability Rights New Jersey v. Velez, No. 3:05-cv-01858 (Apr. 16, 2008).

   In March 2013, Disability Rights NJ finalized a settlement agreement covering both lawsuits that dramatically expanded the availability of community residential placements, diverted unnecessary institutional placements from Developmental Centers, and required the state to find community placements for all 600 eligible Developmental Center residents over a five-year settlement monitoring period. Disability Rights New Jersey, Harmon, Thompson, and Stevens v. Velez, No. 3:08-cv-04723 (March 13, 2013) ECF No. 90. The state met and exceeded its obligations under the settlement agreement by the end of the monitoring period in 2018.

8. A copy of Disability Rights NJ's combined settlement agreement with the State of New Jersey can be found at: https://clearinghouse.net/doc/50027/

9. Disability Rights NJ is a statutory member of the New Jersey Task Force on Long-Term Care Quality and Safety, and as such, participated in a nearly two-year process to make recommendations to the Governor as charged under the statute: L. 2020, c. 88, A. 4481 (2020). As of the date of publishing this report, that report is not yet public.

10. Charles P. Sabatino, Health Affairs, Why nursing homes need a total redesign (April 3, 2023), https://www.healthaffairs.org/content/forefront/why-nursing-homes-need-total-redesign

INVESTIGATION ENDNOTES

11. Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106–402 §§ 101 et seq., 114 Stat. 1677 (2000), codified at 42 U.S.C. §§ 15001 et seq. Disability Rights New Jersey is also the designated protection and advocacy organization for the state of New Jersey under the authority of the following statutes: The Protection and Advocacy for Individuals with Mental Illness Act (PAIMI Act), Pub. L. 99–319, §§ 101 et seq., 100 Stat. 478 (1986), codified and amended at 42 U.S.C. §§ 10801.

    Disability Rights NJ also operates under CAP: Section 112 of the Rehabilitation Act of 1973, as amended by the Workforce Innovation and Opportunity Act (WIOA) of 2014 [See 113th Congress Public Law 113-128]; Protection and Advocacy for Individual Rights (PAIR) Program of the Rehabilitation Act [See 29 U.S.C. § 794e]; The Assistive Technology Act of 2004 [See 108th Congress Public Law 108-364]; Ticket to Work and Work Incentives Improvement Act of 1999, as amended ("TWWIIA") [See 42 U.S.C. § 1320b-21]; PATBI 42 U.S.C. § 300d-53; and Protection and Advocacy for Voting Access Program of the Help America Vote Act [See 52 U.S.C. § 21061-21062]

12. Letter from Gov. Christine Todd Whitman to Robert Williams, Comm'r, Admin. For Developmental Disabilities, Re: Redesignation of New Jersey Protection and Advocacy Agency (Sep. 27, 1994), https://disabilityrightsnj.org/wp-content/uploads/Redesignation-of-NJPA-letter-1994.pdf.

13. 42 U.S.C. §15043(a)(2)(B): Abuse is defined in 45 C.F.R. § 1326.19 as "any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes but is not limited to such acts as: Verbal, nonverbal, mental and emotional harassment; rape or sexual assault; striking; the use of excessive force when placing such an individual in bodily restraints; the use of bodily or chemical restraints which is not in compliance

with Federal and State laws and regulations, or any other practice which is likely to cause immediate physical or psychological harm or result in long term harm if such practices continue."

Neglect is defined as "a negligent act or omission by an individual responsible for providing services, supports or other assistance which caused or may have caused injury or death to an individual with a developmental disability(ies) or which placed an individual with developmental disability(ies) at risk of injury or death" including "failure to: establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care to an individual with developmental disabilities; or provide a safe environment which also includes failure to maintain adequate numbers of trained staff or failure to take appropriate steps to prevent self–abuse, harassment, or assault by a peer." Id.

These definitions can also include and encompass violations of individuals with disabilities civil rights. In addition, the P&A may determine, in its discretion that a violation of an individual's legal rights amounts to abuse, such as if an individual is subject to significant financial exploitation. Id.

14. 142 U.S.C. §15043(a)(2)(I); 42 C.F.R. §1326.25

15. 42 U.S.C. §15043(a)(2)(H); 42 C.F.R. §1326.27

16. As of May 29, 2020, there were 4,949 lab-confirmed deaths attributed to COVID-19, or about 43% of the total deaths official reported in New Jersey. This death total likely undercounts the severity of COVID-19. Officials estimated that the deaths in long-term care facilities were 5,885 when deaths suspected to be linked to COVID-19 are included. Of those, 5,751 were residents and 104 were staff members. Brent Johnson, N.J. Coronavirus Deaths Increase to 11,401, with 157,815 cases. Hospitalizations increase for 2nd day, NJ.com (May. 29, 2020, 1:56 A.M.), https://www.nj.com/coronavirus/2020/05/nj-coronavirus-deaths-increase-to-11401-with-157815-cases-hospitalizations-increase-for-2nd-day.html.

As of August 22, 2022, that number had risen to more than 9,500 COVID-19-related deaths in nursing homes. Lilo H. Stainton, Key stats show NJ nursing homes handling COVID-19, NJ Spotlight News (Aug. 22, 2022), https://www.njspotlightnews.org/2022/08/covid-19-infection-rates-nj-nursing-homes-better-now-than-other-states-aarp-data/.

17. 42 C.F.R. § 431.12

18. NJFamilyCare presentation to the Medical Assistance Advisory Council, Long Term Care and Managed Long Term Services & Supports (April 25, 2019), https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Meeting_Presentations_4_25_19.pdf.

The presentation provided graphs of the numbers of people residing in nursing facilities who were on fee-for-service Medicaid and Medicaid Long Term Supports and Services (MLTSS). This included information solely around individuals on MLTSS. As of February 2018, there were 16,374 nursing facility or special care nursing facility (SCNF) residents on MLTSS. Id. at 68.

The presentation stated that in June 2018, there were 635 individuals with IDD living in nursing facilities in New Jersey and that in December 2018, there were 587. Id. at 74. IDD residents were identified as all those individuals having a DDD cap code, a DDD SPC, or a DDD paycode designation. Id. at 74.

This data was collected from the New Jersey Share Data Warehouse Recipient Table and Claim Universe. Id. It was not clear from the presentation if these individuals were on MLTSS, DD supports, fee-for-service or some other Medicaid Eligibility Group, nor was it clear if the numbers reflected children and youth under the age of 21. NJ Family Care stated they would answer these questions at a future presentation. Medicaid Assistance Advisory Council, Final Meeting Summary (April 25, 2019), https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Mtg_Minutes_4-25-19.pdf, at 28-30.

19. NJFamilyCare presentation to the Medical Assistance Advisory Council, Long Term Care and Managed Long Term Services & Supports, 18-19 (July 25, 2019), https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Meeting_Presentations_7-25-19.pdf.

In State Fiscal Year 2018, there were 190 children and youth under twenty-one on MLTSS, 604 between twenty-two and sixty-four, 177 between sixty-five and eighty-four, and 6 that were eighty-five or older. Id. at 18. The source of this data is NJ DMAHS Share Data Warehouse Table and Claims Universe. Id.

The note at the bottom of the graph explains that the chart includes all MLTSS recipients with an IDD status. Id. NJ FamilyCare also clarified and explained the prior numbers by providing the number of IDD recipients residing in Nursing Facilities including both fee-for-service and MLTSS recipients. Id. at 19.

Michele Andrews of the Office of Business Intelligence at Medicaid explained that for the purposes of this chart, the IDD designation comes from the individual either having contacted DDD on their own, or through a referral from the Division of Aging Services. If that designation is put on the recipient, it will stay with them while on Medicaid, even if they are no longer enrolled in any specific IDD program. If someone did not have either of those two events, and is on Medicaid, NJ FamilyCare would not know about the individual's IDD designation. Medicaid Assistance Advisory Council, Final Meeting Summary, 27-28 (July 25, 2019), https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Mtg_Minutes_7-25-19.pdf.

20. Michele Andrews of the Office of Business Intelligence at Medicaid speaking to Dr. Deborah Spitalnik, Medicaid Assistance Advisory Council, Final Meeting Summary, 29-30 (July 25, 2019), https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Mtg_Minutes_7-25-19.pdf.

21. Manatt, Recommendations to Strengthen the Resilience of New Jersey's Nursing Homes in the Wake of COVID-19, 9 (June 2, 2020), https://www.manatt.com/Manatt/media/Documents/NJ-LTC-Report.pdf.

22. Manatt, Recommendations to Strengthen the Resilience of New Jersey's Nursing Homes in the Wake of COVID-19, 9 (June 2, 2020), https://www.manatt.com/Manatt/media/Documents/NJ-LTC-Report.pdf.

New Jersey's initial preparedness coordination was more focused on external threats to the state, with an emphasis on responding to the risk from international travel. Id. at 7. New Jersey pivoted to focusing on health care delivery system response, though Manatt notes "with greater emphasis on inpatient hospital surge capacity planning and support" which prompted "the prioritization of the distribution of supplies, personal protective equipment (PPE) and other resources to that sector." Id. And it wasn't until March 3 that DOH released guidance directed towards LTC facilities, and only began distributing some PPE to nursing homes "later in the month." Id.

There was no LTC-focused preparedness plan with respect to PPE, staffing back up plans or communication from facilities to families. Id. at 12. And nursing homes were not adequately tied into the larger system of care. Id. The report provides anecdotes from the field which display how inadequate the immediate response to the COVID-19 pandemic was. Id. at 20. Some facilities with 3-and 4-bedded rooms moved patients closer together because they were so seriously short-staffed. Id. This was in disregard to the already established social distancing CDC protocols at the time. The report also seriously calls into question the oversight of non-compliant facilities, writing that the DOH certification and survey and complaint investigatory arm is "under-resourced and understaffed" and that DOH should use its independent authority to impose penalties, revoke a license, appoint a receiver or temporary manager, or cease new admissions for violations of New Jersey requirements. Id. at 39-40.

23. During this period, we achieved these efforts through virtual monitoring and weekly calls with the Department of Health, Division of Behavioral Health and the Department of Human Services, Division of Developmental Disabilities.

24. The New York Times initially reported on the story on April 15, 2020. Tracey Tully, After Anonymous Tip, 17 Bodies Found at Nursing Home Hit By Virus, N.Y. Times (April 15, 2020) https://www.nytimes.com/2020/04/15/nyregion/coronavirus-nj-andover-nursing-home-deaths.html.

The full toll was later reported on April 19. Tracey Tully, Brian M. Rosenthal, Matthew Goldstein, & Robert Gebeloff, 70 Died at a Nursing Home as Body Bags Piled Up. This is What Went Wrong., N.Y. Times (Apr. 19, 2021), https://www.nytimes.com/2020/04/19/nyregion/coronavirus-nj-andover-nursing-home-deaths.html.

25. Developmental Disabilities Assistance and the Bill of Rights Act ("DD Act"), 42 U.S.C. §15043; Protection and Advocacy for Individuals with Mental Illness Act ("PAIMI Act"), 42 U.S.C. §10805(a)(1)(A); Letter from Gwen Orlowski, Exec. Director, to Sonia Velmonte, Administrator, Andover Subacute and Rehabilitation Center 1 & Cynthia Bradford, Administrator Andover Subacute and Rehabilitation Center II (April 18, 2020) (on file with author).

26. New Jersey Dep't of Health, Search for Long-Term Care Facilities (Limecrest Subacute And Rehabilitation Center), https://healthapps.state.nj.us/facilities/fsFacilityDetails.aspx?item=NJ61902 (last visited Aug. 23, 2023).

27. Sussex County, County Administrator Statement concerning Andover Subacute and Rehabilitation Center II (April 17, 2020), https://www.sussex.nj.us/cn/news/index.cfm?NID=50934&jump2=0 (last visited Aug 23, 2023).

28. Based upon data collected by the Long-Term Care Ombudsman, at that time, the total number of individuals in Woodland (formerly Andover II) with mental health diagnoses exceeded 90%. As of December 20, 2021, four hundred and fifty-three (453) residents were living at Woodland. Four hundred and thirty-two (432), 95%, had at least one diagnosis of a psychiatric disorder. There were only twenty-one (21) patients without a noted psychiatric diagnosis, but four (4) of these came to Woodland from psychiatric hospitals. Seven (7) residents had a diagnosis of suicidal ideation.

Note: Typically, federal and state laws use the term "mental illness" when referring to individuals with a mental health disability. In this report, we use the term "mental illness" when speaking about those legal terms. However, we note that "mental illness" is stigmatizing language and use the term "mental health disability" whenever possible. Further, while this investigation primarily looks at individuals with IDD in nursing homes, it is important to note that our work with residents at Woodland, Disability Rights NJ advocacy work, and our legal analysis of federal and state laws throughout this paper, indicate that the current environment for individuals with mental health disabilities is no better than individuals with IDD in nursing homes. While outside the scope of this paper, Disability Rights NJ has serious concerns for individuals with mental health disabilities in NJ nursing homes and will continue to advocate for the rights of those individuals as well.

29. As of April 19, 2020, 70 residents had died from COVID-19. A large but undefined number of that initial death toll of COVID-19 were Andover residents with documented ID, SMI, or TBI. Tracey Tully, Brian M. Rosenthal, Matthew Goldstein, & Robert Gebeloff, 70 Died at a Nursing Home as Body Bags Piled Up. This is What Went Wrong., N.Y. Times (Apr. 19, 2021), https://www.nytimes.com/2020/04/19/nyregion/coronavirus-nj-andover-nursing-home-deaths.html[BP1]

30. Letter from Gwen Orlowski, Executive Director of Disability Rights New Jersey, to Gov. Phil Murphy and Judith Persichilli, the Commissioner of the Department of Health (April 19, 2020), https://static1.squarespace.com/static/5e8f69a0603f6633319de6ed/t/5eb02ddb1d97446802c973eb/1588604380553/Governor%2520Murphy%2520Andover.final2%2520%25281%2529.pdf

31. Immediately upon our resumption of in-person monitoring, we conducted two monitoring visits to Woodland and were appalled by conditions. This coincided with release of news reports that the Department of Health issued a Notice of Violations, Corrective Action, and State Monitoring in February of 2022. With probable cause clearly established, we initiated a full-scale abuse and neglect investigation concurrent with the Department of Health's efforts to address immediate jeopardy concerns with the facility. Our activities included having staff on site at the facility several times a week to observe conditions, speak with residents, and review records that we requested. We also communicated regularly with the Department of Health and the Department of Human Services about our immediate safety concerns and collaborated with the Long-Term Care Ombudsman on efforts.

Woodland administrators and staff consistently tried to interrupt the investigation and obstruct unaccompanied access to the facility and residents. Without unaccompanied access, residents that depend on Woodland staff for every need may worry that any candid complaints they make about the conditions there may be overheard by the management and staff.

Disability Rights NJ monitored the transfer arrangements of all Woodland residents and documented the locations where residents were discharged. We plan to continue monitoring of the facilities where Woodland residents were moved, including speaking with these individuals to ensure individual preferences for placement are respected, including preferences for more integrated settings in the community.

32. Ted Sherman, *Long-troubled nursing home that once housed hundreds of residents is now totally empty,* NJ.com, (Aug. 15, 2022), https://www.nj.com/news/2022/08/long-troubled-nursing-home-that-once-housed-hundreds-of-residents-is-now-totally-empty.html; *See also*, Susan K. Livio & Ted Sherman, *Somebody should care about these patients...,* NJ.com, (Dec. 18, 2022), https://www.nj.com/politics/2022/12/somebody-should-care-about-these-patients.html

33. In Fall 2021, Disability Rights NJ spoke with the state Medicaid agency (DMAHS) to get information about the number of individuals with IDD in nursing homes. Ultimately, Disability Rights NJ decided to use the data from the DDD list.

In March 2022, the state Medicaid agency, DDD, and Division of Aging (DoA) told us that in response to our inquires they had culled a list with 602 individuals with IDD in nursing homes as of February 22, 2022 (this represented people who had a Level I positive screen, see Finding 2), and 18 of those were screened out (for a reason unknown to us), leaving 584 individuals PASRR-eligible for nursing homes. Of those 584 individuals, 38 were being serviced by the Department of Children and Families, 67 were assigned to support coordination or case managers at DDD, and 479 were inactive.

Note: While the State explained to us that different methodologies were used to gather the 2019 data and the 2022 data, the final numbers are substantially similar – the state could account for approximately 560 and 600 residents with IDD in New Jersey nursing homes.

34. Letter from Gwen Orlowski, Executive Director of Disability Rights New Jersey, to Jonathan Seifried, Assistant Comm'r, Division of Developmental Disabilities (April 6, 2022) (on file with author).

35. The original list of individuals from DDD included 587 people. Of those people, 23 were in Developmental Centers or they did not have a facility listed to indicate where they lived, leaving 564 people on the list. When we compare DDD-generated data to PASRR data, we use the 564 DDD number, because we understand the PASRR data includes residents of pediatric nursing homes. Of the remaining 564 people, 39 were individuals living in pediatric facilities. We focused our investigation on the 525 individuals who were all adults in traditional long-term care facilities.

36. While the focus of this report is on the experience of adults with ID in New Jersey nursing homes, Disability Rights NJ conducted outreach to pediatric nursing facilities in New Jersey. Pediatric nursing facilities are a type of special care nursing facility, licensed under N.J.A.C. § 8:85–3.15, which receive a higher reimbursement rate in order to provide intensive nursing services to children under age 22 with high medical needs. N.J.A.C. § 8:85–3.15. See also N.J.A.C. § 8:33H–1.5(a)(describing the requirements for determining the need for pediatric long-term care beds in New Jersey). There are four pediatric nursing facilities in New Jersey: Children's Specialized Hospital Mountainside, Children's Specialized Hospital Toms River, Phoenix Center for Rehabilitation & Pediatrics (in Wanaque) and Voorhees Pediatric Facility. Phoenix Center for Rehabilitation and Pediatrics maintains non-specialty nursing facility units as well as its pediatric unit; the vast majority (39) of the 43 Phoenix residents on our list from DDD resided on the adult units.

There were a total of 39 residents in pediatric nursing facility beds on the list we received from DDD: 3 at Children's Specialized Hospital Mountainside, 4 at Children's Specialized Hospital Toms River, 4 at Phoenix, and 28 at Voorhees.

As part of our outreach, we visited Phoenix Center for Rehabilitation & Pediatrics and Voorhees Pediatric Facility. At both Phoenix and Voorhees, there were many residents on pediatric units who were not included on our list from DDD. As noted above, only four of the residents on our list at Phoenix were in pediatric beds, despite the facility having multiple pediatric units. At Voorhees, the majority of the residents were not on our list. It was clear that our list from DDD was not representative of the resident population of DDD as a whole; for instance, the facility administrator reported that they had residents as young as 3 months old in the facility, while the youngest resident on our list was 10 years old.

In our interviews with residents and stakeholders, we learned that young adults who have received care in pediatric nursing facilities often struggle to find the appropriate care and services when they age out of the children's system of care at age 22. In some cases, young adults may remain in pediatric beds for years due to a lack of appropriate placement in either a community or institutional setting. Six adults with ID on our list, all between the ages of 23 and 33, were either current or previous residents of pediatric nursing facilities.

37. Disability Rights NJ collected and analyzed hundreds of documents from these site visits, including Face Sheets and PASRR Level I and Level II screens. Disability Rights NJ only relied on the demographic and PASRR information contained within those documents when compiling data. If Disability Rights NJ spoke with an individual from the list but did not have documentation which provided demographic information for that individual, Disability Rights NJ did not include any demographic identifiers in its data.

38. N.J.A.C. 10:43-8.3. The Bureau of Guardianship Services (BGS), is responsible for processing and tracking guardianship actions for people served by the Division of Developmental Disabilities (DDD) who have been evaluated according to state law and determined to require a guardian. BGS can serve as guardian of the person if no other appropriate individuals are available to serve.

39. Interview Questions (subject to follow-up questions based on responses):
- Tell me about living here at (facility name)
- Tell me what an average/typical day is like for you.
  - What time do you usually wake up? /What do you do first in the morning when you wake up?
  - oWhen do you eat breakfast?
  - oWhen do you get dressed/get out of bed? etc. ...
  - oWhat time do you get dressed for bed/ get back in bed?
- Are there things you like about living here? What are they? Are there things you dislike about living (here)? What are they?
- Where did you live before here?
- What did you like about living there? / What did you dislike about living there?
- If you could live anywhere you wanted, where would it be?
- Are there things you would like to do that you are not able to do here? What are they?
- Is there someone you trust who knows you very well? If so, who? Would it be okay if we talked to them?
- If you could change anything about (here), what would it be?
- Is there anything else you would like us to know?
- Do you have any questions for me?

40. Guardian Interview Questions (some shortened for length):
- What is your relationship to your family member or dependent who has IDD?
- What events or factors led your family member/dependent to enter the nursing home?
- Are you aware of other places where you family member/dependent has lived?
- How often are you able to visit the individual with IDD in the nursing home?
- Would you like to visit the individual with IDD in the nursing home more often?
- Is your family member/dependent able to communicate their wishes and preferences to you?
- Has your family member/dependent expressed a desire to leave the nursing home and live in another place?
- Do you have any concerns about or see any barriers to your family member/dependent living in their preferred setting?
- Is there anything else you would like to share with us?

KEY FINDING ONE ENDNOTES

41. *Olmstead v. L.C.* ex rel. Zimring, 527 U.S. 581, 119 S. Ct. 2176, 144 L. Ed. 2d 540 (1999); *Frederick L. v. Dep't of Pub. Welfare of Com. of Pennsylvania*, 364 F.3d 487 (3d Cir. 2004); 42 U.S.C. § 12132; Rolland v. Cellucci, 198 F.Supp.2d 25 (D. Mass. 2002), aff'd, 318 F.3d. 42 (1st Cir. 2003)(holding that there is a private right of enforcement to the right to specialized services under the NHRA).

42. Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106–402 §§ 101 et seq., 114 Stat. 1677 (2000), codified at 42 U.S.C. §§ 15001 et seq. Disability Rights New Jersey is also the designated protection and advocacy organization for the state of New Jersey under the authority of the following statutes:

- The Protection and Advocacy for Individuals with Mental Illness Act (PAIMI Act), Pub. L. 99–319, §§ 101 et seq., 100 Stat. 478 (1986), codified and amended at 42 U.S.C. §§ 10801;

- The Protection and Advocacy for Individual Rights (PAIR) Program of the Rehabilitation Act, 29 U.S.C. § 794e;
- The Client Assistance Program (CAP) under Section 112 of the Rehabilitation Act of 1973 (29 U.S.C.A. § 732), as amended by the Workforce Innovation and Opportunity Act (WIOA) of 2014, Pub. L. No- 113-128 (2014), codified at 29 U.S.C. §§ 3101 et seq.;
- The Protection and Advocacy for Assistive Technology (PAAT) Program (29 U.S.C. § 3004), under The Assistive Technology Act of 2004, Pub. L. No. 109-364 (2004), codified at 29 U.S.C. §§ 3001 et seq.;
- The Protection and Advocacy for Beneficiaries of Social Security (PABSS) Program (42 U.S.C. § 1320b-21), under the Ticket to Work and Work Incentives Improvement Act of 1999, as amended, Pub. L. No. 106-170 (1999), codified at 42 U.S.C. §§ 1320b–19 et seq.
- The Protection and Advocacy for Traumatic Brain Injury (PATBI) Program, 42 U.S.C. § 300d-53, under the Children's Health Act of 2000, Pub. L. No. 106-310 (2000), codified at 42 U.S.C. §§284g et seq.; and
- The Protection and Advocacy for Voting Access (PAVA) Program, 52 U.S.C. §§ 21061-21062 under the Help America Vote Act of 2002, Pub. L. No. 107-252 (2002), codified at 52 USCA §§ 20901 et seq.

43. The data is incomplete not only because we did not have a complete list, but because we were not able to gather complete information for each individual on that list, including Face Sheets, PASRR documents, and/or documented demographic. With respect to demographic information, we only include information that we could verify through documentation. For example, we did not indicate the race or gender on our data collection spreadsheet if we didn't have independent documentation to verify same.

44. Disability Rights NJ acknowledges the numerous complications contained in the collection of demographic information such as race, ethnicity, sexual orientation, and gender identity. Disability Rights NJ acknowledges the hesitation, by some, to provide such demographic information for fear that it will only lead to further marginalization of already marginalized people. However, Disability Rights NJ also acknowledges the importance of gathering this information in a way to ensure that the long-term care delivery system, like so many other systems, is not prone to implicit bias and discrimination.

45. Amber Christ and Valencia Sherman-Greenup, *Building an Equitable Medicaid HCBS Infrastructure in NJ for Older Adults*, Justice in Aging (June 2022), https://justiceinaging.org/wp-content/uploads/2022/06/Building-an-Equitable-Medicaid-HCBS-Infrastructure-in-NJ-for-Older-Adults.pdf, *See also*, MLTSS Institute, Advancing Equity Through MLTSS Programs, Advancing States (February 2023), http://www.advancingstates.org/sites/nasuad/files/Advancing%20Equity%20MLTSS%20Feb.%2023.pdf

46. DDD told us that, through the New Jersey Money Follows the Person Program branded as I Choose Home in New Jersey, they reached out to all known IDD clients in 2016 to offer I Choose Home services, and for the most part, people didn't want to leave the nursing home.

47. See Finding #2 and 42 CFR 483.130(l)(3) which require that the Level II determination notice contain the placement options available to the individual consistent with determinations, even if not currently available, to help the state plan.

48. *Olmstead v. L.C.* ex rel. Zimring, 527 U.S. 581, 119 S. Ct. 2176, 144 L. Ed. 2d 540 (1999); Frederick L. v. Dep't of Pub. Welfare of Com. of Pennsylvania, 364 F.3d 487 (3d Cir. 2004); 42 U.S.C. § 12132; Rolland v. Cellucci, 198 F.Supp.2d 25 (D. Mass. 2002), aff'd, 318 F.3d. 42 (1st Cir. 2003)(holding that there is a private right of enforcement to the right to specialized services under the NHRA).

Note: Again, while this paper focuses on individuals with IDD in nursing homes, the State's obligations under Olmstead apply to all residents of nursing homes, regardless of specific disability.

49. NJFamilyCare presentation to the Medical Assistance Advisory Council, Long Term Care and Managed Long Term Services & Supports, 74 (April 25, 2019), https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Meeting_Presentations_4_25_19.pdf

50. NJFamilyCare presentation to the Medical Assistance Advisory Council, Long Term Care and Managed Long Term Services & Supports, 19 (July 25, 2019), https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Meeting_Presentations_7-25-19.pdf.

51. In addition to the list produced on April 14, 2022, in March 2022, the state Medicaid agency, DDD, and DoAS told Disability Rights NJ that in response to our inquires they had culled a list with 602 individuals with IDD in nursing homes as of February 22, 2022 (this represented people who had a Level I positive screen, see Finding 2), and 18 of those were screened out (for a reason unknown to us), leaving 584 individuals PASRR-eligible for nursing homes. Of those 584 individuals 38 were being serviced by the Department of Children and Families, 67 were assigned to support coordination or case managers at DDD, and 479 were in active.

52. Ultimately, Disability Rights NJ decided to go with the list from DDD, which included 587 people, as opposed to the information provided by DMAHS, including information provided at the MACC meetings. Of those 587 people, 23 were in Developmental Centers or they did not have a facility listed to indicate where they lived. Of the remaining 564 people, 39 were individuals living in pediatric facilities. The 525 individuals left were all adults in traditional long-term care facilities. The April 2022 numbers were slightly different from the numbers provided verbally in March 2022.

Please note that the New Jersey Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families, Paul Aronsohn, in his 2022 Annual Report, also published data from DDD about the number of individuals with IDD admitted to nursing homes; however, we did not rely on this same data for our report. "Over the past 4.3 years, individuals with intellectual or developmental disabilities have been admitted to New Jersey nursing homes on at least 2,268 occasions – about 1,587 (70%) of these occasions have involved long-term stays; about 1,255 (55%) have involved people under the age of 63 years." Paul S. Aronsohn, New Jersey Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families 2022 Annual Report (May 30, 2023), https://nj.gov/treasury/njombudsman/documents/2022-Annual-Report.pdf

53. Disability Rights NJ conducted site visits at 71 facilities, in all 21 counties. During those site visits, we would introduce ourselves to nursing home staff including administrators, social workers, and nursing staff, explain the purpose of our visit, and share the names of individuals with IDD we intended to visit. On more than a dozen occasions, staff told us there were other residents with IDD not on the list and shared their names. To the extent possible, we met with and/or had conversations with those individuals too.

Disability Rights NJ also included the Bureau of Guardianship Services and the Office of the Public Guardian in its investigation, including an interview, participation in a paper survey, and providing us with releases so we could request and review Fact Sheets and PASRR documentation. During these interactions, we heard from BGS and OPG that they knew of at least several residents with IDD in nursing homes who were not on the DDD April 2022 list.

54. PASRR data for this time period was not as widely available due to COVID-19-related PASRR policy choices on the part of New Jersey and the Centers for Medicare and Medicaid Services. CMS allowed states to request an 1135 waiver of the requirements that the PASRR assessments be taken for new admissions to nursing facilities. As CMS noted at the time, "Section 1919(e)(7) of the Act allows Level I and Level II assessments to be waived for 30 days. All new admissions can be treated like Exempted Hospital Discharges. Centers for Medicare and Medicaid Services, Section 1135 Waiver Flexibilities - New Jersey Coronavirus Disease 2019 (March 23, 2020), https://www.medicaid.gov/state-resource-center/disaster-response-toolkit/federal-disaster-resources/entry/54033. CMS allowed all new nursing facility admissions to be treated like Exempted Hospital Discharges. Id. After 30 days, new admissions with mental illness (MI) or intellectual disability (ID) should receive a Resident Review as soon as resources become available, said CMS. Id. This waiver was in effect from March 2020, until November 2021.

New Jersey's waiver of the PASRR requirements ended with the termination of the State of Emergency on November 15, 2021. Dep't of Human Services, COVID-19 Policy Guidance for Long-Term Care Medicaid Certified Facilities: Resumption of In-Person Clinical Eligibility Determinations and PASRR Resident Review Requirements Pre-Admission (Nov. 1, 2021), https://nj.gov/humanservices/assets/slices/DoAS%20COVID19%20Clinical%20Eligibility%20and%20PASRR%20Communication%20for%20LTC%20Providers%2011.1.21.pdf

Below are the questions Disability Rights NJ asked DDD:

1. Number of Level 1 screens does by acute care and rehab hospitals.
2. Number of Level 1 screens done by NF staff for admissions from community.
3. Number of Legal 1 screens that are negative for IDD and so individual can be admitted to NF.
4. Number of Level 1 screens positive for either IDD or both SMI/IDD that are referred to DDD for Level II.
5. Number of Positive Level 1s with the 30-Day Exempted Hospital Discharge designation submitted to DDD.

a. The number of these Level 1 exemptions submitted with the attending hospital physician's certification attached.
b. The number of NF completed Level II referrals/determinations processed by day 40.

6. For PASRR Level IIs completed by DDD, the number of Division determinations on: [Assuming there are quantifiable responses on the Level II]
   a. Determination that evidence substantiates that person meets PASRR definition of IDD - # of Yes, # of No
   b. SS needed - # of Yes, # of No
   c. Most appropriate, least restrictive setting identified [ex: # of: assisted living, group home, supervised apt, family home, own home, etc.]

Numbers for Categorical Determinations at Level II
   a. Terminal Illness
   b. Severe Physical Illness
   c. Respite
   d. APS referrals
   e. Dementia for DDD

8. Level II determinations outcomes: number of negatives and number of positives
9. Number of appeals filed

55. We also received PASRR data from family advocates, which align with information we received from DDD.

56. In a March 2022 meeting with DDD, we were told that an individual could be referred more than once for a Level I evaluation, so there could be duplicates in these numbers - we don't know if they represent unique individuals. Also, we asked for Level I evaluations positive for IDD or IDD/MI, so numbers could include both a positive for IDD and a positive for both IDD.

57. In response to a question about the number of Level II Evaluations and Determinations completed before day 40 for people on Exempted Hospital Discharge status who remained in a nursing home for more than 30 days, DDD answered that they did not have that data.

See also, PASRR Technical Assistance Center, What is the Exempted Hospital Discharge? (Jan. 25, 2018), https://www.pasrrassist.org/combined/What-is-the-Exempted-Hospital-Discharge%3F ("While not required, states may choose to perform a Level I screen for individuals being admitted to a NF under the (hospital exemption) as a way to track individuals who might later require a Level II.")

58. Data available from January 1, 2022 through December 31, 2022. Level I + information provided to DRNJ by a family advocate.

59. Data available from January 1, 2023 through June 31, 2023.

60. In addition, Disability Rights New Jersey received the data for March 2022 through December 2022 from a family advocate, who received the data through a records request response by Division of Developmental Disabilities dated January 23, 2023.

61. The Minimum Data Set (MDS), a required quarterly assessment which every nursing facility must complete for each resident, is a powerful tool for advocates and states hoping to identify and transition people with disabilities institutionalized in nursing homes back to the community. 42 U.S.C. § 1395i-3(f)(6); 42 U.S.C. § 1395r(f)(6); 42 C.F.R. § 483.20; 42 C.F.R. § 483.215; See also PASRR Technical Assistance Center, PASRR and the Minimum Data Set (MDS), PASRR Technical Assistance Center (Oct. 6, 2016) (July 7, 2014), https://www.pasrrassist.org/webinars/PASRR-and-the-Minimum-Data-Set-(MDS). Research Data Assistance Center, Long Term Care Minimum Data Set (MDS) 3.0, Centers for Medicaid and Medicare Services, https://resdac.org/cms-data/files/mds-30#:~:text=View%20Data%20Documentation,or%20Medicaid%2C%20regardless%20of%20payer (accessed August 31, 2023).

62. PASRR Technical Assistance Center, PASRR and the Minimum Data Set (MDS), PASRR Technical Assistance Center (July 8, 2014), https://www.pasrrassist.org/_files/ugd/d693e6_dbd9fe87038d4f24b8b2f8204b863f6f.pdf, at 6.

63. Centers for Medicaid and Medicare Services, Minimum Data Set (MDS) 3.0 for Nursing Homes and Swing Bed Providers, https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/NHQIMDS30 (accessed August 31, 2023)

64. 42 C.F.R. § 483.20(b)(2) and (c); PASRR Technical Assistance Center, Slides, PASRR and the Minimum Data Set (MDS),PASRR Technical Assistance Center (Oct. 6, 2016) (July 7, 2014), https://www.pasrrassist.org/webinars/PASRR-and-the-Minimum-Data-Set-(MDS) at 7.

65. Definition of "Mental Illness" (MI): 42 C.F.R. § 483.102(b)(1)
Definition of Intellectual Disability (IID): 42 C.F.R. § 483.102(b)(3)
Definition of Related Condition (RC): 42 C.F.R. § 435.1010
For full definitions please see endnote 93 infra.

66. PASRR Technical Assistance Center, Slides, PASRR and the Minimum Data Set (MDS), PASRR Technical Assistance Center (July 7, 2014), https://www.pasrrassist.org/webinars/PASRR-and-the-Minimum-Data-Set-(MDS), at 13.

67. Centers for Medicaid and Medicare Services, Long-Term Care Facility Resident Assessment 3.0 User's Manual, (Version 1.17.1, effective October 2019), https://downloads.cms.gov/files/mds-3.0-rai-manual-v1.17.1_october_2019.pdf, at A-21 – A-25.

CMS has recently finalized the updated RAI Manual for the MDS 3.0. The manual does not contain material changes to the PASRR-related items. Centers for Medicaid and Medicare Services, Long-Term Care Facility Resident Assessment 3.0 User's Manual, (Draft Version 1.18.11, effective October 2023, https://www.cms.gov/files/document/finalmds-30-rai-manual-v11811october2023.pdf, at A-30 – A-34.

68. **Important Revision Note:** In November 2023, Disability Rights NJ removed the Person First report from our website to make corrections to address ambiguities and updates in the presentation and our interpretation of the CMS MDS Frequency Report. On April 23, 2024, we re-released the Person First report with corrective revisions to parts of Key Finding One and the recommendations and findings related to the data. Disability Rights NJ initially published the Person First report on October 2, 2023. In November 2023, NJ DHS brought discrepancies with the data to our attention, and we promptly pulled the report from our website. As a matter of full transparency, Disability Rights NJ wants to explain how we misinterpreted the MDS data.

Disability Rights NJ initially pulled MDS data from the MDS website in late 2020 for an internal memo. We again pulled data from the MDS site in early 2021 for the same memo. During both instances, we recorded the same number, 2,630, to represent the number of individuals who had a positive Level II PASRR screen for Q4 in 2019. For the Person First report, we again pulled that same number, 2,630, in late 2022. We reported this same number (along with other quarters) in the October Person First report based on a good-faith reliance on CMS's MDS Frequency Report data as displayed at the four separate times we viewed it. When we went to verify the data in July and August 2023, the original website had been decommissioned. We now understand that 2,630 (and the other quarters we initially reported) represented the total "yes" and "no" responses to questions A1510B and A1510C. However, since multiple staff members at Disability Rights NJ, at multiple instances over the course of two years, interpreted the data in the same way, we believe that the numbers published in our October Person First report reflect the ambiguous way the data was presented on the now-decommissioned MDS website at the times we viewed the data between 2020 and 2023.

After this error was brought to our attention, we sought to understand how we misinterpreted that data. As CMS had decommissioned the original website and launched an overhauled MDS website, the data was now presented in a new, much clearer manner, and we were unable to verify the source of the previous ambiguity. In addition, the 2019 MDS numbers were removed entirely from the new MDS website. We requested the 2019 data directly from CMS, and after several months, CMS provided us the raw data on March 14, 2024. The corrected numbers are reflected in this revised version of the report, consistent with the revised MDS Frequency Report.

69. Disability Rights NJ used the excel spread sheet linked here https://disabilityrightsnj.org/wp-content/uploads/Updated-Master-MDS-Data-Spreadsheet.xlsx to capture and analyze the MDS PASRR data for questions A1500 and A1510 A, B, and C for Q1 2019 through Q4 2023 (though only Q1 and Q2 2023 are in the body of the report, as only those 2023 quarters were available when the report was first published in October 2023).

In this excel spread sheet, we compare the total number of "yes" answers to A1500 (by quarter) to the total "yes" and "no" answers for each A1510 question – A, B, C. The difference in the answers demonstrates some level of human error in answering the questions. For example, the FY19 Q1 total A1500 "yes" answers was 2,526. The total A1510A "yes" and "no" was 2,525 (a difference of one); the total A1510B "yes" and "no" was 2,525 (a difference of one); and the total A1510C "yes" and "no" was 2,523 (a difference of three). Slightly different totals can be found throughout all the quarters, demonstrating some degree of human error since one would expect the totals to be the same; total number of "yes" answers to A1500 should equal total number of "yes" and "no" answers to A1510A, B, and C.

In this excel spread sheet, we also compare the total number of "yes" answers to A1500 (by quarter) to the total combined "yes" answers to A1510A, A1510B, and A1510C, and measure the difference between those numbers, which we believe represents duplicate "yes" answers in A1510. In other words, the same person may have answered "yes" to more than one of the sub-questions - A1510A, A1510B, and A1510C. For example, a person may have answered "yes" to having MI and ID, or MI and RC, or ID and RC, or all three.

Looking again at FY19, Q1, the number of "yes" answers to A1500 is 2,526, while the number of "yes" answers to A1510A, B, and C combined is 2,703, a difference of 177 additional "yes" answers to A1510 than to A1500. This means that up to 177 unique people who answered "yes" to A1500, answered "yes" to either two or three of the sub-questions for A1510 (answers of "yes" to all three would lower the number of unique individuals from 177).

From our analysis, we predicted the possible lowest number of people with ID and RC, by quarter, by adding the number of "yes" answers for A1510B and A1510C, and then subtracting out the greatest possible duplicative "yes" answers; and we predicted the possible highest number of by simply adding the ID and RC together, assuming all of the duplication was between MI and ID and/or MI and RC.

We used this analysis and range of ID and RC "yes" answers to compare to the data provided to us by the Medicaid agency and DDD through the MAAC meetings in 2019 and the data provided to us by DDD in April 2022, based on March 2022 information, and show the State's undercounting in relevant quarters. Admittedly, the MDS PASRR definitions of ID and RC may not align perfectly with the definition of "IDD" used by the state Medicaid agency and/or DDD to capture the number of people with IDD in New Jersey nursing homes.

Finally, we note that significant data exist capturing the overlap of individuals diagnosed with IDD and mental health disabilities. See Lineberry, S., et. al., Co-Occurring Mental Illness and Behavioral Support Needs in Adults with Intellectual and Developmental Disabilities (Feb. 5, 2023), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9899157/pdf/10597_2023_Article_1091.pdf. This data show that individuals with IDD are more likely to have mental health disabilities than individuals without IDD. Id. While the data vary, conservatively, approximately 33% of individuals with a diagnosis of IDD also have a mental health diagnosis compared to approximately 21% of individuals without IDD. Id. See also Pinals, D., et. al., Persons With Intellectual and Developmental Disabilities in the Mental Health System: Part 1. Clinical Considerations (March 2022), https://ps.psychiatryonline.org/doi/epdf/10.1176/appi.ps.201900504.

Disability Rights NJ found that there is a lack of data around the number of individuals with both an intellectual and developmental disability. There are, of course, individuals who have both an intellectual and developmental disability. However, the diagnoses for intellectual disabilities are separate and distinct from developmental disabilities, and we could not find good data to identify exactly how many people have both diagnoses. There is, however, significant research related to the overlap in a mental health diagnosis and ID or DD. Therefore, the data suggest that total number of people with IDD (combined total A1510B and A1510C) in nursing homes is likely closer aligned to the higher end of the predictive number in our MDS Frequency Report, supra at 24-25. This is because the number of duplicative answers to A1510 A, B, or C is likely a "yes" answer to A1510A (MI) and a "yes" to either A1510B (ID) or A1510C (RC) since there is a significant overlap between MI diagnoses and ID or DD.

70. Disability Rights NJ reached these percentages for the relevant time frames December 2018/January 2019 and March/April 2022 as follows:

- 37%: July 2019 MACC meeting, Medicaid/DDD reported that in December 2018 there were 611 (including Fee for Service (FFS)) people with IDD in NF. CMS MDS Frequency reports 974 (highest predictive) for the first quarter of 2019. That is undercounting MDS number by 363 people which translates into 37% undercounting.

- 23%: July 2019 MACC Meeting, Medicaid/DDD reported that in December 2018 there were 611 (including FFS) people with IDD in NF. CMS MDS Frequency reports 797 (lowest predictive) for the first quarter of 2019. That is undercounting MDC number by 186 people which translates into 23% undercounting.

- 24%: DDD April 14, 2022, based on 1st quarter numbers first provided verbally in March, in the 1st quarter 2022 there were 564 people with IDD in NF (587 minus 23 in DCs or no address). CMS MDS Frequency reports 744 (highest predictive) for the first quarter of 2022. That is undercounting MDS number by 180 people which translates into a 24% undercounting.

- 12%: DDD April 14, 2022, based on 1st quarter numbers first provided verbally in March, in the 1st quarter 2022 there were 564 people with IDD in NF (587 minus 23 in DCs or no address). CMS MDS Frequency reports 641

(lowest predictive) for the first quarter of 2022. That is undercounting MDS number by 77 people which translates into a 12% undercounting.

71. A similar decrease of nearly 20% of the IDD population in nursing homes is borne out if the lowest predictive number is used: 774 in 4th quarter 2019; 756 in 1st quarter 2020; and 620 in 2nd quarter 2020.

This represents a decrease of more than 150 people with IDD between December 2019 and June 2020, or approximately 20% of the IDD nursing facility population over this period of time.

KEY FINDING TWO ENDNOTES

72. As originally enacted, the law was titled "Preadmission Screening and Annual Resident Review." No Compliance Actions Before Effective Date of Guidelines; Preadmission Screening and Annual Resident Review, Pub.L. 101-508, Title IV, § 4801(b)(1) (1990), 104 Stat. 1388-213. It was amended in 1996 to remove the requirement for annual review, 42 USC §1396r((b)(F)), instead having a requirement of a resident review upon a change in the resident's condition. NURSING HOME FACILITY RESIDENT REFORM, PL 104–315, October 19, 1996, 110 Stat 3824.

73. 42 C.F.R. §§ 483.100-483.138.

74. PASRR Technical Assistance Center, Transcript, *PASRR Learning Module 3: CFR Compliance in the Level II Evaluation Process and Resident Review*, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_554e5966341443aba2b4ac87964233b5.pdf, at 3 ("PASRR is an essential component in a state *Olmstead* compliance strategy. A poor PASRR system creates risks for litigation or is a poor defense if there is litigation around *Olmste[a]d.*")

75. 42 C.F.R. § 440.150(a) "ICF/IID services" means those items and services furnished in an intermediate care facility for Individuals with Intellectual Disabilities if the following conditions are met: (1) The facility fully meets the requirements for a State license to provide services that are above the level of room and board; (2) The primary purpose of the ICF/IID is to furnish health or rehabilitative services to persons with Intellectual Disability or persons with related conditions; (3) The ICF/IID meets the standards specified in subpart I of part 483 of this chapter.(4) The beneficiary with Intellectual Disability for whom payment is requested is receiving active treatment, as specified in § 483.440 of this chapter. (5) The ICF/IID has been certified to meet the requirements of subpart C of part 442 of this chapter, as evidenced by a valid agreement between the Medicaid agency and the facility for furnishing ICF/IID services and making payments for these services under the plan."

76. 42 C.F.R. § 483.116(b)(2)("[t]he State must provide or arrange for the provision of the specialized services needed by the individual while he or she resides in the NF"). *See also* PASRR Technical Assistance Center, Transcript, PASRR Learning Module 5: Specialized Services, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_1207eb8648f64db0bc41c1d2212be631.pdf, at 3 ("specialized services are provided while the individual resides in the nursing facility. This is why inpatient psychiatric treatment or services in an intermediate care facility for intellectual disability should not be considered as specialized services.")

77. This confusion likely has roots in the original PASRR statutory language that used the term "active treatment," a term also used to define the services provided in an ICF-IDD. The PASRR statute was amended in 1990 to remove the term "active treatment" and replace it with the term "specialized services. Omnibus Budget Reconciliation Act of 1990, Pub. L. 101-508, 104 Stat. 1388.

78. Note that the regulations provide a separate definition of specialized services for "mental illness" at 42 C.F.R. § 483.120(a)(1): "For mental illness, specialized services means the services specified by the State which, combined with services provided by the NF, results in the continuous and aggressive implementation of an individualized plan of care that— (i) Is developed and supervised by an interdisciplinary team, which includes a physician, qualified mental health professionals and, as appropriate, other professionals. (ii) Prescribes specific therapies and activities for the treatment of persons experiencing an acute episode of serious mental illness, which necessitates supervision by trained mental health personnel; and (iii) Is directed toward diagnosing and reducing the resident's behavioral symptoms that necessitated institutionalization, improving his or her level of independent functioning, and achieving a functioning level that permits reduction in the intensity of mental health services to below the level of specialized services at the earliest possible time."

79. 42 C.F.R. § 483.120(a)(2).

80. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 5: Specialized Services, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_1207eb8648f64db0bc41c1d2212be631.pdf, at 3.

81. 42 C.F.R. § 483.116(b)(2)("[t]he State must provide or arrange for the provision of the specialized services needed by the individual while he or she resides in the NF"); 42 C.F.R. § 483.120(b)("[t]he state must provide or arrange for the provision of specialized services, to all NF residents with MI or IID"); Rolland v. Cellucci, 198 F. Supp. 2d 25, 29 (D. Mass. 2002), aff'd sub nom.Rolland v. Romney, 318 F.3d 42 (1st Cir. 2003) (holding that in passing the NHRA, "Congress mandated that states provide active treatment [specialized services] to such nursing facility residents deemed in need"); See also PASRR Technical Assistance Center, Transcript, PASRR Learning Module 5: Specialized Services, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_1207eb8648f64db0bc41c1d2212be631.pdf, at 3.

82. 42 C.F.R. § 481.21(b)(1)(iii); 42 C.F.R. § 483.116(b)(2).

83. For instance, the state could arrange for an individual with IDD residing to attend a day program while they reside in the facility. After transition to a community setting, the individual can continue to attend the day program through a home and community based services (HCBS) waiver. See PASRR Technical Assistance Center, Transcript, PASRR Learning Module 5: Specialized Services, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_1207eb8648f64db0bc41c1d2212be631.pdf, at 5 for further examples

84. 42 C.F.R. § 483.120(a)(2)("[f]or intellectual disability, specialized services means the services specified by the State…").

85. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 5: Specialized Services, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_1207eb8648f64db0bc41c1d2212be631.pdf.

86. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 5: Specialized Services, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_1207eb8648f64db0bc41c1d2212be631.pdf.

87. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 5: Specialized Services, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_1207eb8648f64db0bc41c1d2212be631.pdf.

88. *Note: These same principles apply to specialized services for individuals with mental health disabilities or "MI".*

89. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 5: Specialized Services, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_1207eb8648f64db0bc41c1d2212be631.pdf.

90. The NHRA includes the following:

- Required services nursing homes must provide to residents, including standards for these services. These services include periodic assessments, comprehensive care plans (42 U.S.C. §§ 1395i–3(b)(3)(A), 1396r(b)(3)(A)), nursing services (42 U.S.C. §§ 1395i–3(b)(4)(A)(i), 1396r(b)(4)(A)(i)), social services (42 U.S.C. §§ 1395i–3(b)(4)(A)(ii), 1396r(b)(4)(A)(ii)), rehabilitation services including specialized rehabilitation services for individuals with MI and/or IDD (42 U.S.C. §§ 1395i–3(b)(4)(A)(v), 1396r(b)(4)(A)(v), 42 C.F.R. § 483.65), pharmaceutical services (42 U.S.C. §§ 1395i–3(b)(4)(A)(iii), 1396r(b)(4)(A)(iii)), dietary services (42 U.S.C. §§ 1395i–3(b)(4)(A)(iv), 1396r(b)(4)(A)(iv)), and if the facility has more than 120 beds, a full-time social worker (42 U.S.C. §§ 1395i–3(b)(7), 1396r(b)(7)).

- The establishment of a Residents' Bill of Rights, including the right to be free from abuse and neglect, freedom from physical restraints, the right to exercise self-determination as well as protections against involuntary transfer or discharge. (42 U.S.C. §§ 1395i–3(c), 1396r(c)).

- A certification and monitoring process that requires states to conduct surveys and resident interviews, focused on residents' rights, quality of care, quality of life, and the services provided to residents. 42 U.S.C. §§ 1395i–3(g); 1396r(g). Where nursing homes are out of compliance with the federal law, the NHRA provides enforcement mechanisms, including plans of correction, civil monetary penalties, denial of payment for all new Medicare or Medicaid admissions, denial of payment for all Medicaid and Medicare residents; and termination of provider agreements. 42 U.S.C. §§ 1395i–3(g); 1396r(g).

  Martin Klauber and Bernadette Wright, AARP Public Policy Institute, *The 1987 Nursing Home Reform Act* (February 2001) https://www.aarp.org/home-garden/livable-communities/info-2001/the_1987_nursing_home_reform_act.html.

  While the NHRA only applies to nursing homes certified by Medicare or Medicaid (with PASRR requirements specific to Medicaid-certified facilities), its provisions and protections apply to all residents of those certified nursing homes regardless of the payment source for the individual resident.

Ninety-one percent of New Jersey's 349 licensed nursing homes are Medicaid-certified and accordingly, residents of those nursing homes have nearly all of the rights and protections of the NHRA and PASRR. H.R. Rep. No. 100-391(I), at 458 (1987), *reprinted* in 1987 U.S.C.C.A.N. 2313-201, 2313-278 (noting that ""[i]n the view of the [Budget] Committee, all residents of nursing facilities should receive high quality care, regardless of their source payment.") The exceptions are the following 30 nursing homes:

Twenty nursing homes in New Jersey accept only Medicare or Private Pay: The Arbor at Laurel Circle (Bridgewater), Care Connection Rahway, CareOne at Cresskill, CareOne at Ridgewood Avenue (Paramus), CareOne at Somerset Valley (Bound Brook), CareOne at Wayne, Community Medical Center TCU (Toms River), Continuing Care at Lantern Hill (New Providence), Hackensack Meridian Health Prospect Heights Care Center (Hackensack), Harrogate (Lakewood), Hoboken University Medical Center TCU (Hoboken), Jewish Home for Rehabilitation and Nursing (Freehold), Lutheran Social Ministries Cranes Mill (West Caldwell), New Jersey Veterans Memorial Home Menlo, New Jersey Veterans Memorial Home Paramus, New Jersey Veterans Memorial Home Vineland, Skilled Nursing at Fellowship Vllage (Basking Ridge), Spring Hills Post Acute Livingston, Willowbrooke Court Skilled Care at Evergreens (Moorestown), Winchester Gardens Health Care Center (Maplewood).

Ten nursing homes are Private Pay only: Carepoint Health- Bayonne Hospital Center TCU (Bayonne), Francis E. Parker Memorial Home New Brunswick, Francis E. Parker Memorial Home Piscataway, Friends Village at Woodstown, Garden Terrace Nursing Home (Chatham), Hackensack-UMC Mountainside (Montclair), Holland Christian Home (North Haledon), Little Nursing Home (Montclair), New Jersey Firemen's Home (Boonton), Parker at Monroe.

91. 42 U.S.C. § 1396r(e)(7). While this paper is focused on an analysis of New Jersey's PASRR process as it relates to individuals with IDD, Disability Rights NJ has also observed that similar problems permeate the PASRR process for individuals with MI. While investigating abuse and neglect at Woodlands Nursing and Rehabilitation Center (formerly Andover) during the pandemic, Disability Rights NJ obtained PASRR documents for residents with MI which revealed issues similar to those detailed here. Disability Rights NJ therefore recommends that any review and overhaul of the PASRR process that the State conducts include a review and revision of the PASRR process for individuals with MI.

92. NURSING HOME FACILITY RESIDENT REFORM, PL 104–315, October 19, 1996, 110 Stat 3824. See also PASRR Technical Assistance Center, *PASRR Learning Module 1: An Introduction to CFR Compliance* (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-1%3A-An-Introduction-to-CFR-Compliance.

Disability Rights NJ recognizes that the flaws in the New Jersey PASRR system have historical roots, going back decades, related both to the failure of CMS to issue updated federal regulations since 1992 and New Jersey needing to modernize its statute and regulations to reflect a post-*Olmstead* legal world and CMS's evolving best practices for PASRR implementation.

CMS provides technical assistance to states through the PASRR Technical Assistance Center (PTAC) established in 2009 to address problems raised by three OIG Reports, in 2001 and 2007. PTAC provides six PASRR 101 Learning Modules. Through those Learning Modules, CMS acknowledges the early and continuing confusion in state PASRR systems. For example, PASRR Learning Module 1: An Introduction to CFR Compliance.

93. Definition of "Mental Illness" (MI): 42 C.F.R. § 483.102(b)(1):
An individual is considered to have a serious mental illness (MI) if the individual meets the following requirements on diagnosis, level of impairment and duration of illness: (i) Diagnosis. The individual has a major mental disorder diagnosable under the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revised in 1987. Incorporation of the 1987 edition of the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, was approved by the Director of the Federal Register in accordance with 5 U.S.C. 552(a) and 1 CFR part 51 that govern the use of incorporation by reference. This mental disorder is— (A) A schizophrenic, mood, paranoid, panic or other severe anxiety disorder; somatoform disorder; personality disorder; other psychotic disorder; or another mental disorder that may lead to a chronic disability; but (B) Not a primary diagnosis of dementia, including Alzheimer's disease or a related disorder, or a non-primary diagnosis of dementia unless the primary diagnosis is a major mental disorder as defined in paragraph (b)(1)(i)(A) of this section. (ii) Level of impairment. The disorder results in functional limitations in major life activities within the past 3 to 6 months that would be appropriate for the individual's developmental stage. An individual typically has at least one of the following characteristics on a continuing or intermittent basis: (A) Interpersonal functioning. The individual has serious difficulty interacting appropriately and communicating effectively with other persons, has a possible history of altercations, evictions, firing, fear of strangers, avoidance of interpersonal relationships and social isolation; (B) Concentration, persistence, and pace. The individual has serious difficulty in sustaining focused attention for a long enough period to permit the completion of tasks commonly found in work settings or in work-like structured activities occurring in school or home settings, manifests difficulties in concentration, inability to complete simple tasks within an established time period, makes frequent errors, or requires assistance in the completion of these tasks; and (C) Adaptation to change. The individual has serious difficulty in adapting to typical changes in circumstances associated with work, school, family, or social interaction, manifests agitation, exacerbated signs and symptoms associated with the illness, or withdrawal from the situation, or requires intervention by the mental health or judicial system. (iii) Recent treatment. The treatment history indicates that the individual has experienced at least one of the following: (A) Psychiatric treatment more intensive than outpatient care more than once in the past 2 years (e.g., partial hospitalization or inpatient hospitalization); or (B) Within the last 2 years, due to the mental disorder, experienced an episode of significant disruption to the normal living situation, for which supportive services were required to maintain functioning at home, or in a residential treatment environment, or which resulted in intervention by housing or law enforcement officials.

Definition of Intellectual Disability (IID): 42 C.F.R. § 483.102(b)(3):
An individual is considered to have intellectual disability (IID) if he or she has— (i) A level of retardation (mild, moderate, severe or profound) described in the American Association on Intellectual Disability's Manual on Classification in Intellectual Disability (1983). Incorporation by reference of the 1983 edition of the American Association on Intellectual Disability's Manual on Classification in Intellectual Disability was approved by the Director of the Federal Register in accordance with 5 U.S.C. 552(a) and 1 CFR part 51 that govern the use of incorporations by reference;2 or (ii) A related condition as defined by § 435.1010 of this chapter.

Definition of Related Condition (RC): 42 C.F.R. § 435.1010:
Persons with related conditions means individuals who have a severe, chronic disability that meets all of the following conditions: (a) It is attributable to—(1) Cerebral palsy or epilepsy; or (2) Any other condition, other than mental illness, found to be closely related to Intellectual Disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons. (b) It is manifested before the person reaches age 22. (c) It is likely to continue indefinitely. (d) It results in substantial functional limitations in three or more of the following areas of major life activity: (1) Self-care. (2) Understanding and use of language. (3) Learning. (4) Mobility. (5) Self-direction. (6) Capacity for independent living.

94. NURSING HOME FACILITY RESIDENT REFORM, PL 104–315, October 19, 1996, 110 Stat 3824.See also PASRR Technical Assistance Center, PASRR Learning Module 1: An Introduction to CFR Compliance (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-1%3A-An-Introduction-to-CFR-Compliance.

95. 42 C.F.R. §§ 483.100-483.138.

96. Medicaid Program; Preadmission Screening and Resident Review, 85 Fed. Reg. 9990 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483). On April 17, 2020, CMS extended comment period; however, those final regulations were never adopted.

97. Medicaid Program; Preadmission Screening and Resident Review, 85 Fed. Reg. 9990 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483). On April 17, 2020, CMS extended comment period; however, those final regulations were never adopted.

98. Medicaid Program; Preadmission Screening and Resident Review, 85 Fed. Reg. 9990 (Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483); PASRR Technical Assistance Center, PASRR Learning Module 1: An Introduction to CFR Compliance, PASRR Technical Assistance Center (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-1%3A-An-Introduction-to-CFR-Compliance (discussing the impact of other laws and developments on PASRR over time.)

99. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 1: Intro to CFR Compliance, (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_3d0455a0703446e7ab8f57bae91e6282.pdf, at 1. See Daniel R. Levinson, Inspector General, U.S. Department of Health and Human Services, Preadmission Screening and Resident Review for Younger Nursing Facility Residents with Mental Retardation (Jan. 2007) https://oig.hhs.gov/oei/reports/oei-07-05-00230.pdf.

100. 42 C.F.R. § 483.126. The regulation says that placement of an individual with MI or IID in a NF "may be considered appropriate only when the individual's needs are such that he or she meets the minimum standards for admission and the individual's needs for treatment do not exceed the level of services which can be delivered in the NF to which the individual is admitted either through NF services alone or, where necessary, through NF services supplemented by specialized services provided by or arranged for by the State." See also Preadmission Screening and Resident Review, Medicaid.gov, https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/preadmission-screening-and-resident-review/index.html (last visited Aug. 9, 2023).

The 2020 proposed rule sought to make clear that PASRR is "to allow people to live in the optimal setting for that individual, as reflected by the individual's needs and preferences." Medicaid Program; Preadmission Screening and Resident Review, 85 FR 9990-01.

Preadmission Screening and Resident Review, Medicaid.gov, https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/preadmission-screening-and-resident-review/index.html (last visited Aug. 9, 2023). See also PASRR Technical Assistance Center, PASRR Learning Module 1: An Introduction to CFR Compliance (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-1:A-An-Introduction-to-CFR-Compliance, at Slide 24. (Image below displays a chart that highlights the hierarchy of supports and services that moves from most restrictive to least restrictive).

Most Restrictive	Needs can be met only in an acute, inpatient setting such as an acute hospital, IMD or ICF/IID
	Needs can be met in a NF, with additional specialized services
	Needs can be met in a NF, with only NF services and specialized rehabilitative services
Least Restrictive	Needs can be met in an appropriate community-based setting

101. 42 C.F.R. § 483.132.

102. For more information about specialized services, see "What are Specialized Services for IDD?" at pages 28-29.

103. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 1: Intro to CFR Compliance, (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_3d0455a0703446e7ab8f5-7bae91e6282.pdf, at 11.

104. 42 U.S.C. § 1396r(b)(3)(F); 42 U.S.C. § 1396r(e)(7). Money Follows the Person/I Choose Home NJ, Section Q, and home and community-based services (HCBS) are three powerful Medicaid initiatives which require and contribute to efforts to divert people with disabilities (including ID) from nursing facilities. MFP, first authorized by the Deficit Reduction Act of 2005 (Pub. L. 109-171 (2006) 120 Stat. 4) is a demonstration that provides federal funds to states to support Medicaid beneficiaries in transitioning from institutions to the community. Medicaid.gov, Money Follows the Person, https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html (accessed August 25, 2023).

Section Q, part of the Minimum Data Set (MDS), is a powerful tool for advocates and states to identify and transition people with disabilities in nursing homes into the community. The expanded Section Q questions added in the 2010 update to MDS, known as MDS 3.0, have provided a powerful starting place for states to connect people with disabilities who want to transition to the community to appropriate supports and services. Section Q requires facilities to affirmatively ask a resident and/or their family if they want to return to the community and refer those who answer yes to a designated local contact agency to receive information about community options. Centers for Medicaid and Medicare Services, Long-Term Care Facility Resident Assessment 3.0 User's Manual, (Draft Version 1.18.11, effective October 2023), https://www.cms.gov/files/document/draftmds-30-rai-manual-v11811october2023.pdf. In New Jersey, the local contact agency is the Office of Community Choice and Options (OCCO) in the Division of Aging and Community Services. New Jersey Department of Human Services, Section Q (April 2014), https://www.nj.gov/humanservices/dmahs/home/Section_Q_Training.pdf, at 9.

In New Jersey, home and community-based waiver services, as well as HCBS services under Managed Long Term Supports and Services (MLTSS) are provided through the state's FamilyCare Comprehensive Demonstration. Medicaid.gov, New Jersey FamilyCare Comprehensive Demonstration Approval (March 30, 2023) https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf. Both Money Follows the Person and Section Q can result in referrals that connect eligible individuals to HCBS.

Centers for Independent Living (CILs) are another key source of advocacy for individuals wanting to leave nursing homes and return to the community. CILs are funded through the Rehabilitation Act of 1973 and offer: information and referral, independent living skills training, peer counseling, individual and systems advocacy, services that help people with disabilities transition from institutions to the community or those at risk of entering institutions, and services to help youth transition to adult life. The Administration for Community Living, Centers for Independent Living, https://acl.gov/programs/aging-and-disability-networks/centers-independent-living (accessed September 13, 2023). Information about the CIL serving each county in New Jersey is available at https://www.njsilc.org/.

105. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 1: An Introduction to CFR Compliance, https://www.pasrrassist.org/_files/ugd/d693e6_3d0455a0703446e7ab8f57ba-e91e6282.pdf, PASRR Technical Assistance Center (Oct. 6, 2016) at 5. See also PASRR Technical Assistance Center, Transcript, PASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88abc05a4a034e7cb9340abdcb5a2d5e.pdf at 5-6 (discussing recovery-focused issues states should consider in determining their MI screening processes); Medicaid Program; Preadmission Screening and Resident Review, 85 Fed. Reg. 9990 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483) (summarizing the purpose of the proposed regulations as "making the process more streamlined and person-centered.")

106. On March 13, 2020, as a result of the presidential proclamation that the U.S. COVID-19 outbreak constituted a national emergency, the Secretary of DHHS invoked his authority to waive and modify Medicaid-related requirements of the Social Security Act. The authority took effect on March 15, 2020, with a retroactive effective date of March 1, 2020. Letter from Calder Lynch, Deputy Administrator and Director, Centers for Medicaid and Medicare Services, to Jennifer Langer Jacobs, Assistant Commissioner, New Jersey Division of Medical Assistance and Health Services (March 23, 2020) (available at https://www.medicaid.gov/state-resource-center/disaster-response-toolkit/federal-disaster-resources/entry/54033.)

In the COVID-19 Declaration Blanket Waiver for Health Care Facilities, CMS permitted a waiver of 42 C.F.R. 483.20(k), thus allowing nursing homes to admit new residents who had not received preadmission screening as part of PASRR. However, other requirements of PASRR remained in place; CMS specified that "level one assessments may be performed post admission," and "on or before the 30th day of admission, new patients admitted to nursing homes with a mental illness or intellectual disability should be referred promptly by the nursing home" to the State for Level II Resident Review. Centers for Medicaid and Medicare Services, COVID-19 Emergency Declaration Blanket Waivers for Health Care Facilities (updated October 13, 2022) (https://www.cms.gov/files/document/covid-19-emergency-declaration-waivers.pdf), at 17.

107. 442 UCS § 438.192(a).

108. CMS requires state mental health and intellectual disability agencies (which in NJ are, respectively, the Division of Mental Health and Addiction Services, and the Division of Developmental Disabilities) to coordinate efforts with the state Medicaid agency (in NJ, the Division of Medical Assistance and Health Services). Notably, CMS requires states to coordinate PASRR processes "to the maximum extent possible" with routine resident assessments using the RAI as required under 42 C.F.R. § 483.20(b). 42 C.F.R. § 483.108(c).

The state Medicaid agency may only overturn a PASRR determination through the appeals process; it may not countermand "determinations made by the State mental health or intellectual disability authorities…either in the claims process or through other utilization control/review processes or by the State survey and certification agency." 42 C.F.R. § 483.108(a). However, determinations by the state mental health and intellectual disability agencies must both be consistent with federal PASRR regulations and the "supplemental criteria adopted by the state Medicaid agency under its approved state plan." 42 C.F.R. § 483.108(b).

Note also that the federal PASRR regulations specify distinct evaluation processes for the state mental health and state intellectual disability agencies. While the state intellectual disability agency may conduct the evaluation in the case of suspected ID, "[a]n evaluator that is independent of the MH agency must complete the MH evaluation." PASRR Technical Assistance Center, Transcript, *PASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations,* PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88a-bc05a4a034e7cb9340abdcb5a2d5e.pdf at 7. Compare 42 C.F.R. § 483.136(c)(2) ("the State intellectual disability authority, using appropriate personnel, as designated by the State, must validate that the individual has IID or is a person with a related condition and must determine whether specialized services for intellectual disability are needed" and 42 C.F.R. § 483.134(d) ("a qualified mental health professional, as designated by the State, must validate the diagnosis of mental illness and determine whether a program of psychiatric specialized services is needed.")

109. A Level I screen may be initiated for a person already residing in a nursing home if a new MI or ID is detected. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 1: An Introduction to CFR Compliance, https://www.pasrrassist.org/_files/ugd/d693e6_3d0455a0703446e7ab8f57ba-e91e6282.pdf, PASRR Technical Assistance Center (Oct. 6, 2016) at 9 ("[i]f there is a NF admission, there may still be PASRR involvement at a later date… as a result of a new MH/ID/RC being identified for someone who did not have those concerns identified on their first screening, which would lead to the NF completing a Level I or notifying the appropriate state authority.")

110. Under the federal regulations, inter-facility transfers (from NF to NF, "with or without an intervening hospital stay") "are subject to annual resident review rather than preadmission screening." 42 C.F.R. § 483.106(e)(4)(i). Similarly, individuals readmitted to a facility after receiving care from a hospital are also subject to resident review but not preadmission screening. 483.106(e)(3). Additionally, A state may include arrangements for PASRR in its provider agreements with out-of-State facilities or reciprocal interstate agreements. 42 C.F.R. § 483.110(b).

42 C.F.R. § 483.128(b) ("[e]valuations performed under PASRR and PASRR notices must be adapted to the cultural background, language, ethnic origin and means of communication used by the individual being evaluated"); 42 C.F.R. § 483.128(c) ("PASRR evaluations must involve…[t]he individual being evaluated… "[t[he individual's legal representative, if one has been designated under State law," and "[t]he individual's family if…[a]vailable" and if [t]he "individual or the legal representative agrees to family participation."

111. 42 C.F.R. § 483.128(b) ("[e]valuations performed under PASRR and PASRR notices must be adapted to the cultural background, language, ethnic origin and means of communication used by the individual being evaluated"); 42 C.F.R. § 483.128(c) ("PASRR evaluations must involve…[t]he individual being evaluated… "[t[he individual's legal representative, if one has been designated under State law," and "[t]he individual's family if…[a]vailable" and if [t]he "individual or the legal representative agrees to family participation."

112. In the 2020 proposed regulations, CMS proposed to replace the current regulation at 42 C.F.R. § 483.126 with a new section, titled "Level I identification criteria." Medicaid Program; Preadmission Screening and Resident Review, 85 Fed. Reg. 9990 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483), at 10004. Proposed § 483.126 included a new provision explaining "that the state's PASRR program must have a Level I screening process to identify all individuals with possible MI or ID who require Preadmission Screening… or Resident Review", as well as definitions of "possible MI" and "possible ID." 85 Fed. Reg. 10004. See also PASRR Technical Assistance Center, Transcript, PASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88a-bc05a4a034e7cb9340abdcb5a2d5e.pdf at 4.

113. PASRR Technical Assistance Center, Transcript, P*ASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations,* PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88a-bc05a4a034e7cb9340abdcb5a2d5e.pdf at 5.

114. CMS requires state mental health and intellectual disability agencies (which in NJ are, respectively, the Division of Mental Health and Addiction Services, and the Division of Developmental Disabilities) to coordinate efforts with the state Medicaid agency (in NJ, the Division of Medical Assistance and Health Services). Notably, CMS requires states to coordinate PASRR processes "to the maximum extent possible" with routine resident assessments using the RAI as required under 42 C.F.R. § 483.20(b). 42 C.F.R. § 483.108(c).

The state Medicaid agency may only overturn a PASRR determination through the appeals process; it may not countermand "determinations made by the State mental health or intellectual disability authorities…either in the claims process or through other utilization control/review processes or by the State survey and certification agency." 42 C.F.R. § 483.108(a). However, determinations by the state mental health and intellectual disability agencies must both be consistent with federal PASRR regulations and the "supplemental criteria adopted by the state Medicaid agency under its approved state plan." 42 C.F.R. § 483.108(b).

Note also that the federal PASRR regulations specify distinct evaluation processes for the state mental health and state intellectual disability agencies. While the state intellectual disability agency may conduct the evaluation in the case of suspected ID, "[a]n evaluator that is independent of the MH agency must complete the MH evaluation." PASRR Technical Assistance Center, Transcript, PASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88a-bc05a4a034e7cb9340abdcb5a2d5e.pdf at 7. Compare 42 C.F.R. § 483.136(c)(2) ("the State intellectual disability authority, using appropriate personnel, as designated by the State, must validate that the individual has IID or is a person with a related condition and must determine whether specialized services for intellectual disability are needed" and 42 C.F.R. § 483.134(d) ("a qualified mental health professional, as designated by the State, must validate the diagnosis of mental illness and determine whether a program of psychiatric specialized services is needed.")

CMS considers the determination made by the state ID agency (or state MI agency) a legal document comprised of the determination and written notification containing appropriate appeal rights.

115. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 3: CFR Compliance in the Level II Evaluation Process and Resident Review, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_554e5966341443aba2b4ac87964233b5.pdf, at 3.

116. 42 C.F.R. § 483.128(c) ("PASRR evaluations must involve…[t]he individual being evaluated… "[t[he individual's legal representative, if one has been designated under State law," and "[t]he individual's family if…[a]vailable" and if [t]he "individual or the legal representative agrees to family participation."

117. PASRR Technical Assistance Center, Transcript, *PASRR Learning Module 3: CFR Compliance in the Level II Evaluation Process and Resident Review,* PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_554e5966341443aba2b4ac87964233b5.pdf, at 3 ("[t]he Level II evaluation is… states' front line for ensuring that individuals are diverted from unnecessary admission to nursing facilities…"); See also Preadmission Screening and Resident Review, 85 Fed. Reg. 9990, 10016 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483) (describing the "statutory goals" of the PASRR statute as "avoiding unnecessary NF placements.")

118. "Note that…people with known diagnoses of MI or ID are still considered to have 'possible MI or ID' until the Level II evaluator has confirmed the individual meets the definition of MI or ID." Medicaid Program; Preadmission Screening and Resident Review, 85 Fed. Reg. 9990 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483), at 10004.

119. 42 C.F.R. § 483.128(m)(1). The Level II Evaluation must be completed by an evaluator who meets qualifications established by the state. The State may designate the mental health professionals who are qualified to perform the evaluations required including the comprehensive drug history, the psychosocial evaluation, comprehensive psychiatric evaluation, and functional assessment. 42 C.F.R. § 483.134(c)(2)(i-ii). See also PASRR Technical Assistance Center, PASRR Learning Module 1: An Introduction to CFR Compliance (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-1:A-An-Introduction-to-CFR-Compliance, at Slide 10.

120. 42 C.F.R. § 483.128(i)(5).

121. 42 C.F.R. § 483.130(m)(4) ("[w]herever the resident chooses to reside, the State must meet his or her specialized services needs.")

122. In the 2020 proposed regulations, CMS clarified that the "NF levels of services evaluation required by PASRR involves a more comprehensive and holistic evaluation than most NF level of care assessments," and that "performing a NF level of care assessment" does not "satisf[y] the requirement to evaluate individuals with MI or ID for NF level of services." Preadmission Screening and Resident Review, 85 Fed. Reg. 9990, 10010 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483).

123. The term "placement options" was initially promulgated in the 1992 regulations and is defined as including nursing facility admission. 42 C.F.R. § 483.130(m)(1). In the 2020 proposed regulations, CMS proposed to remove the placement options listed at 42 C.F.R. § 483.130(m), due to the agency's view that they were duplicative of requirements at 42 C.F.R. § 483.116 and § 483.118. Preadmission Screening and Resident Review, 85 Fed. Reg. 9990, 10009 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483).

124. 42 C.F.R. § 483.132.

125. In New Jersey, NF level of care is defined at N.J.A.C. 8:85-2.1 and in the New Jersey FamilyCare 1115 Demonstration Approval. Medicaid.gov, New Jersey FamilyCare Comprehensive Demonstration Approval (March 30, 2023) https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf at 61. The individual must require hands on assistance in at least three activities of daily living (ADLs), or, if the person has a cognitive impairment resulting in at least minimal impairment with decision making and requires supervision, cueing, or other assistance with at least three ADLs.

126. 42 C.F.R. § 483.321(1)&(2)

127. 42 C.F.R. § 483.21(stating that the nursing home is responsible for developing both baseline care plans and comprehensive care plans that incorporate PASRR recommendations and determinations.)

128. 42 C.F.R. § 483.120. If a nursing facility disagrees with the findings of the PASRR, it must be noted in the medical record.

129. CMS considers the determination made by the state ID agency (or state MI agency) a legal document comprised of the determination and written notification containing appropriate appeal rights. PASRR Technical Assistance Center, Transcript, *PASRR Learning Module 3: CFR Compliance in the Level II Evaluation Process and Resident Review,* PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_554e5966341443aba2b4ac87964233b5.pdf, at 10.

130. 42 C.F.R. § 483.128(c) ("PASRR evaluations must involve…[t]he individual being evaluated… "[t[he individual's legal representative, if one has been designated under State law," and "[t]he individual's family if…[a]vailable" and if [t]he "individual or the legal representative agrees to family participation."

131. 42 C.F.R. § 483.130(l); PASRR Technical Assistance Center, Transcript, *PASRR Learning Module 3: CFR Compliance in the Level II Evaluation Process and Resident Review*, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_554e5966341443aba2b4ac87964233b5.pdf, at 10.

132. Nursing Facility (NF) Level of Care means care, treatment and services provided to individuals who are unable to care for themselves independently. Individuals who require NF level of care are those who are fully or partially dependent in several Activities of Daily Living (ADLs). ADLs include bathing, toileting, dressing, eating, and mobility. However, as the proposed regulations to PASRR point out, this should not be confused with what it means to need NF services. Medicaid Program; Preadmission Screening and Resident Review, 85 FR 9990-01. NF level of care assessments are the functional needs assessments states use to confirm basic eligibility for NF admission on the basis of functional needs. Id. The evaluation of NF level of services required by PASRR involves a more comprehensive and holistic evaluation than most NF level of care assessments. Id. Level of Care determinations are made according to state-specific criteria, while Level of Service is a federally-mandated standard followed by all PASRR evaluators. Id.

133. The term "placement options" was initially promulgated in the 1992 regulations and is defined as including nursing facility admission. 42 C.F.R. § 483.130(m)(1). In the 2020 proposed regulations, CMS proposed to remove the placement options listed at 42 C.F.R. § 483.130(m), due to the agency's view that they were duplicative of requirements at 42 C.F.R. § 483.116 and § 483.118. Preadmission Screening and Resident Review, 85 Fed. Reg. 9990, 10009 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483). CMS is clear that inpatient settings are not "specialized services," although some states, including New Jersey, define specialized services as only able to be provided in inpatient settings. PASRR Technical Assistance Center, Transcript, *PASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations*, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88abc05a4a034e7cb9340abdcb5a2d5e.pdf at 9.

134. 42 C.F.R. §§ 431.200, et seq., 42 C.F.R. § 431.220(a)(3) specifically grants the right to a hearing for "any individual who requests it because he or she believes the State has made an erroneous determination with regard to the preadmission and annual resident review requirements." Unlike other Medicaid determinations, the State is not required to provide advance notice of PASRR determinations but is otherwise required to follow the procedures of this section. 42 C.F.R. § 431.213(g).

135. 42 U.S.C. § 1396r(e)(7)(C)(ii)("[t]he nursing facility must examine each resident no less frequently than once every 3 months and, as appropriate, revise the resident's assessment to assure the continuing accuracy of the assessment"); PASRR Technical Assistance Center, Transcript, *PASRR Learning Module 3: CFR Compliance in the Level II Evaluation Process and Resident Review*, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_554e5966341443aba2b4ac87964233b5.pdf, at 30.

Note: There is still mention of annual resident reviews in New Jersey law, see N.J.A.C. 10:54-7.7(c).

136. 42 C.F.R. §§ 431.200, et seq., 42 C.F.R. § 431.220(a)(3) specifically grants the right to a hearing for "any individual who requests it because he or she believes the State has made an erroneous determination with regard to the preadmission and annual resident review requirements." Unlike other Medicaid determinations, the State is not required to provide advance notice of PASRR determinations, but is otherwise required to follow the procedures of this section. 42 C.F.R. § 431.213(g).

137. 42 C.F.R. § 483.106(b)(2).

138. 42 C.F.R. § 483.128. The federal regulations also allow "Categorical Determinations", for example if someone enters a nursing home on hospice or for respite, that are discussed herein. 42 C.F.R. § 483.130(d).

139. The criteria for the 30 Day Exempted Hospital Discharge are that the individual was in hospital for acute medical care (not a psychiatric hospital or ICF-ID), is being admitted directly to the nursing home for treatment of the same acute medical condition, and is expected to be in the nursing facility for fewer than 30 days. 42 U.S.C. § 1396r(e)(7); 42 C.F.R. § 483.106(b)(2)(i)("An Exempted Hospital Dischargee means an individual…[w]ho is admitted to any NF directly from a hospital after receiving acute inpatient care at the hospital" (emphasis added)). See also PASRR Technical Assistance Center, Transcript, PASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88abc05a4a034e7cb9340abdcb5a2d5e.pdf at 7.

140. 42 C.F.R. § 483.106 ("If an individual who enters a nursing home as an Exempted Hospital Dischargee is later found to require more than 30 days of NF care, the State mental health or intellectual disability authority must conduct an "annual resident review" within 40 calendar days of admission); *See* also 42 U.S.C. § 196r(e)(7)(iii).

141. PASRR Technical Assistance Center, Transcript, *PASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations,* PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88a-bc05a4a034e7cb9340abdcb5a2d5e.pdf at 7.

142. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 2: *CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations*, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88a-bc05a4a034e7cb9340abdcb5a2d5e.pdf at 7.

143. 42 C.F.R. § 483.106(m)(2)(i).

144. 42 C.F.R. § 483.128(i); 42 C.F.R. § 483.130(b); 42 C.F.R. § 483.130(c). States may choose to establish categories for group determinations that allow the evaluator to review existing data that is current, accurate, and sufficient to readily determine that the person with MI or IDD fit the category established by the state, such that the full individualized Level II process does not need to be completed (the state can use an "abbreviated" determination), at least for a period of time.

145. PASRR Technical Assistance Center, Transcript, PASRR Learning Module 2: CFR Compliance in the Level I Screening Process, Exempted Hospital Discharges, and Categorical Determinations, PASRR Technical Assistance Center (Oct. 6, 2016) https://www.pasrrassist.org/_files/ugd/d693e6_88a-bc05a4a034e7cb9340abdcb5a2d5e.pdf at 8.

146. 42 C.F.R. § 483.128(i).

147. PASRR Determination Criteria, 42 C.F.R. § 483.130(d-f) (2016). The regulations provide for the following categories, some of which are time limited: *Time-limited so likely to resolve over time.* Delirium (state specifies, once delirium clears). Emergency/Adult Protective Services- (maximum 7 days). Respite (brief and finite, time limit set by state). For these time-limited categories, the Level I screening is required; it is permissible for a decision that specialized services are not need based on the category, at least during the allowable time limit; an abbreviated Level II report and notice is required, and if the person remains in the nursing home longer than the applicable time limit, the full individualized Level II process, including an evaluation for specialized services, is required once the time limit is over.

148. PASRR Determination Criteria, 42 C.F.R. § 483.130(d-f) (2016). Terminal illness that meets Medicare criteria for hospice. Severe physical illness (e.g. coma, ventilator dependence, COPD, Parkinson's and Huntington's disease, ALS, congestive heart failure) which result in a level of impairment so severe that the person could not be expected to benefit from specialized services. Convalescent care from an acute physical illness that required hospitalization and does not meet criteria for Exempt Hospital Discharge (state should specific a time limit). 42 C.F.R. § 483.130(d). For the advanced Categorical Determinations above, the Level I screening is required; unlike time limited categories, an individual determination regarding specialized services is required. New I don't think this is happening in NJ. 42 C.F.R. § 483.130(f). The State mental health and intellectual disability authorities may make Categorical Determinations that specialized services are not needed in the provisional, emergency and respite admission situations identified in § 483.130(d)(4)–(6). In all other cases, except for 42 C.F.R. § 483.130(h), a determination that specialized services are not needed must be based on a more extensive individualized evaluation under 42 C.F.R. § 483.134 or 42 C.F.R. § 483.136. An abbreviated Level II report and notice is required, and, if the person's condition improves, a full resident review, including an evaluation for specialized services, is required. 42 C.F.R. § 483.130(d).

149. PASRR Determination Criteria, 42 C.F.R. § 483.128(m); 42 C.F.R. § 483.130(h). A state may also choose to have allow for Categorical Determinations for people with IDD who are also diagnosed with dementia. It is important to note that the Level II evaluation is required in these instances; however, it is permissible to make a determination that specialized services are not need based on the category. Otherwise, a Level I screen, and nursing facility level of care determination is also required. The Level II Determination must include notice.

150. Preadmission Screening and Resident Review, 85 Fed. Reg. 9990 (proposed Feb. 20, 2020) (to be codified at 42 CFR Parts 431, 433, 435, 441, and 483).

151. The Center for Public Representation, Comments on Proposed Rule: Preadmission Screening and Resident Review CMS-2418-P (May 18, 2020), https://www.regulations.gov/comment/CMS-2020-0015-0167; Consortium for Citizens with Disabilities, Long-Term Services and Supports Co-Chairs, Comments on Proposed Rule: Preadmission Screening and Resident Review CMS-2418-P (May 19, 2020), https://www.regulations.gov/comment/CMS-2020-0015-0146; Disability Rights California and Justice in Aging, , Comments on Proposed Rule: Preadmission Screening and Resident Review CMS-2418-P (May 20, 2020), https://www.regulations.gov/comment/CMS-2020-0015-0237; Disability Rights New Jersey, Comments on Proposed Rule: Preadmission Screening and Resident Review CMS-2418-P (May 20, 2020), https://www.regulations.gov/comment/CMS-2020-0015-0250.

152. While this paper does not include New Jersey's regulatory approach to PASRR as related to mental health, Disability Rights New Jersey notes that the State's definition of specialized services for "mental illness" is also incorrect. In its investigation of Woodland, Disability Rights New Jersey found that the PASRR system was just as broken for individuals identified as having MI as it was for individuals with IDD. Further comments on the issues with this part of the PASRR system are forthcoming.

153. Identifying information from examples are redacted.

154. 42 C.F.R. § 483.130(c).

155. 42 C.F.R. § 483.130(g).

156. The only mention of specialized services on the DDD Level II Evaluation and Determination form occurs on page 7, in the Determination section, where the evaluator is given the option to check off a box labeled "The individual would benefit from Specialized Services. There is no need for rehabilitation at this time, nor is there a medical condition that exceeds or would impede access to specialized services in the community." This section clearly combines the determination of the need for specialized services and the need for rehabilitation, which, as noted within this paper, should be separate determinations. This section is followed by a section titled "Determination of Community Based Services," which gives the evaluator the option to check off boxes marked "Support Coordination Services," "Individual Supports," and "Day Habilitation Services," all services which are not currently available long-term to individuals in nursing homes in New Jersey under the State Plan.

157. In response to Disability Rights NJ's query regarding how many Level II Evaluation and Determinations conducted between 2019-2021 identified the most appropriate, least restrictive setting for the individual, DDD replied: "This is discussed through the person-centered planning process with the individual and their planning team. Options counseling is provided through the PASRR process. E-mail from Jonathan Seifried, Assistant Commissioner, Division of Developmental Disabilities, to Michael Brower, Legal Director, Disability Rights New Jersey, Disability Rights New Jersey (September 29, 2022) (on file with author).

158. N.J. Stat. Ann. § 30:4D-17.10(d) (1988).

159. N.J. Stat. Ann. § 30:4D-17.11 (1988).

160. N.J. Stat. Ann. § 30:4D-17.13 (1988).

161. 42 U.S.C. § 1396r(a) (defining "nursing facility" as "an institution (or a distinct part of an institution) which … is primarily engaged in providing to residents… skilled nursing care and related services for residents who require medical or nursing care…")(emphasis added).

There is not a standard definition for NF Level of Care across the country, federal law allows each state to determine own criteria. NJ's nursing home level of care for adults is found at N.J.A.C § 8:85-2.1 and 2.2 in the NJFamilyCare Demonstration Waiver at Special Term and Condition 5.6.

162. 42 C.F.R. § 483.20; 42 C.F.R. § 483.21.

163. 42 U.S.C. § 1396r(e)(7); 42 C.F.R. §§ 483.1 et seq.

164. Disability Rights NJ recognizes that the federal law encourages efficiency and allows coordination of the MDS 3.0 with PASRR. 42 U.S.C. § 1396r(b)(3)(E)("[s]uch assessments shall be coordinated with any State-required preadmission screening program to the maximum extent practicable in order to avoid duplicative testing and effort"); 42 C.F.R. § 483.21(c)("[t]o the maximum extent practicable, in order to avoid duplicative testing and effort, the PASRR must be coordinated with the routine resident assessments required by § 483.20(b)"). However, it is important to note that the reporting requirement at 42 U.S.C. § 1396r(b)(3)(E) is done by the nursing facility, not the Medicaid agency responsible for the MDS 3.0 or the intellectual disability agency under PASRR. Any coordination of these processes must be done such that individuals retain their rights under PASRR.

165. N.J.A.C. § 8:85-1.8, titled "Pre-Admission Screening (PAS), admission and authorization" embeds and conflates PAS and PASRR processes and has not been updated since 2017. Under this section of the regulations, these functions currently sit with the Department of Health and the Department of Health and Senior Services, which no longer exists. *See* endnote 171 *supra*.

166. In New Jersey, NF level of care is defined at N.J.A.C. § 8:85-2.1 and in the New Jersey FamilyCare 1115 Demonstration Approval. Medicaid.gov, New Jersey FamilyCare Comprehensive Demonstration Approval (March 30, 2023) https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf at 61.

167. N.J. Stat. Ann. § 8:85-1.8.

168. N.J.A.C. § 10:54-7.1(c)("[t]he PASRR assessment and authorization process shall be subsumed within the State's PAS protocols.").

169. N.J. Stat. Ann. § 8:85-1.2.

170. Under N.J.A.C. § 10:54-7.1, the now-defunct Department of Health and Senior Services is designated as the agency responsible for administering the Preadmission Screening Program.

171. N.J.A.C. § 8:85-1.2.

172. N.J.A.C. § 10:54-7.1(a) (defining specialized services for individuals with MI as inpatient psychiatric care and providing no definition of specialized services for individuals with IDD; N.J.A.C. § 8:85-1.2; N.J.A.C. § 10:52-1.11(b); N.J.A.C. § 8:85-1.8(d)(iv) (stating that if a "PASRR results in a determination that no specialized services are required, the Department shall approve NF placement" and if a "PASRR results in a determination that the individual requires specialized services… then NF placement is inappropriate"); New Jersey Department of Human Services, Division of Medical Assistance & Health Services, *New Jersey Medicaid State Plan*, Attachment 4: Payments and Rates, https://www.state.nj.us/humanservices/dmahs/info/state_plan/Attachment4_Payments_and_Rates.pdf,, at 493.

173. New Jersey Department of Human Services, Division of Medical Assistance & Health Services, N*ew Jersey Medicaid State Plan*, Attachment 4: Payments and Rates, https://www.state.nj.us/humanservices/dmahs/info/state_plan/Attachment4_Payments_and_Rates.pdf,, at 493. Despite the apparent conflict with the PASRR regulations promulgated in 1992, CMS approved this portion of the State Plan on January 13, 1995. *Id.*

174. New Jersey Department of Human Services, Preadmission Screening and Resident Review (PASRR) Overview (Revised) (January 2019), https://www.state.nj.us/humanservices/doas/documents/PASRR_PowerPoint.pdf, at 7 and 8.

175. We reach this conclusion based upon the definition of specialized services in New Jersey which precludes nursing home admission if a person with IDD is found to need specialized services. While some people were found to need specialized services in the PASRR data provided by DDD, our review of the examples of PASRR Level II screens and the template form showed only an option for specialized services in the community, not in a nursing home. From this, we reasonably conclude that some individuals were found to need specialized services and were, therefore, denied nursing home placement.

176. Disability Rights NJ reviewed a total of 129 PASRR Level 1 Screens that were positive for IDD/RC, and a total of 83 PASRR Level II Evaluations and Determinations.

177. Under New Jersey's PASRR scheme, individuals identified as needing specialized services are not permitted to be admitted to the nursing home. Assuming New Jersey's PASRR system is working as designed (albeit inconsistently with federal law), the individuals in this category were not admitted to the nursing home.

178. *See generally* PASRR Technical Assistance Center, *Good Practices for Adopting Waiver Services in the Nursing Facility Benefit: A Specialized Services State Plan Amendment,* PASRR Technical Assistance Center (Nov. 20, 2020) https://www.pasrrassist.org/webinars/Good-Practices-for-Adopting-Waiver-Services-in-the-Nursing-Facility-Benefit%3A-A-Specialized-Services-State-Plan-Amendment.

179. *Note: While this paper focuses on nursing homes residents with IDD and how PASRR can be used to foster HCBS, Olmstead principles apply to all people in a nursing home and the state of NJ must develop and implement a "comprehensive, effectively working plan for placing" nursing home residents with disabilities in community-based programs. Frederick L. v. Dep't of Pub. Welfare of Com. of Pennsylvania, 364 F.3d 487, 498 (3d Cir. 2004), citing Olmstead, 527 U.S. at 605–06. That plan could include PASRR, Section Q, MFP, Medicaid waivers and a housing strategy.*

Section Q, a part of the Minimum Data Set (MDS), is a powerful tool for advocates and states hoping to identify and transition people with disabilities institutionalized in nursing homes. The expanded Section Q questions added in the 2010 update to the current version of the MDS, known as MDS 3.0, have provided a powerful initial starting place for states to connect people with disabilities who want to transition to the community to appropriate supports and services. Section Q requires facilities to affirmatively ask a resident and/or their family if they want to return to the community and refer those who answer yes to a designated local contact agency to receive information about community options. Centers for Medicaid and Medicare Services, Long-Term Care Facility Resident Assessment 3.0 User's Manual, (Draft Version 1.18.11, effective October 2023), https://www.cms.gov/files/document/draftmds-30-rai-manual-v11811october2023.pdf. In New Jersey, the local contact agency is the Office of Community Choice and Options (OCCO) in the Division of Aging and Community Services. New Jersey Department of Human Services, *Section Q* (April 2014), https://www.nj.gov/humanservices/dmahs/home/Section_Q_Training.pdf, at 9.

180. New Jersey Department of Human Services, Division of Medical Assistance & Health Services, New Jersey Medicaid State Plan, Attachment 4: Payments and Rates, https://www.state.nj.us/humanservices/dmahs/info/state_plan/Attachment4_Payments_and_Rates.pdf, at 494-6.

181. 42 C.F.R. § 483.130.

182. At the time of this report, DDD provided us with numbers through the end of June 2023.

183. At the time of this report, DDD provided us with numbers through the end of June 2023.

184. PASRR Technical Assistance Center, Slides, Good Practices for Adopting Waiver Services in the Nursing Facility Benefit: A Specialized Services State Plan Amendment,PASRR Technical Assistance Center (Nov. 20, 2020) https://www.pasrrassist.org/_files/ugd/85e9d6_1bf91d9c2da64f0db938cbb8ee808344.pdf, at 3-7.

185. PASRR Technical Assistance Center, Slides, Good Practices for Adopting Waiver Services in the Nursing Facility Benefit: A Specialized Services State Plan Amendment,PASRR Technical Assistance Center (Nov. 20, 2020) https://www.pasrrassist.org/_files/ugd/85e9d6_1bf91d9c2da64f0db938cbb8ee808344.pdf, at 7.

186. Approval Document, Connecticut State Plan Amendment, TN: 19-0009, Centers for Medicare and Medicaid Services, https://www.medicaid.gov/sites/default/files/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/CT/CT-19-0009.pdf.

187. Approval Document, Washington State Plan Amendment, TN: 15-0012, Centers for Medicare and Medicaid Services, https://www.medicaid.gov/sites/default/files/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/WA/WA-15-0012.pdf

188. Approval Document, Nebraska State Plan Amendment, TN: 18-0001, Centers for Medicare and Medicaid Services, https://www.medicaid.gov/sites/default/files/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/NE/NE-18-0001.pdf.

189. Approval Document, Texas State Plan Amendment, TN: 17-0020, Centers for Medicare and Medicaid Services, https://www.medicaid.gov/sites/default/files/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/TX/TX-17-0020.pdf.

190. Lilo H. Stainton, *Thousands of NJ families frustrated by long wait for disability services*, NJ Spotlight News (Aug. 21, 2023), https://www.njspotlightnews.org/2023/08/thousands-nj-families-frustrated-with-long-wait-for-adequate-disability-services/; P. Kenneth Burns, *How New Jersey is feeling the impact of the affordable housing shortage,* WHYY PBS (Apr. 7, 2023), https://whyy.org/articles/new-jersey-affordable-housing-shortage-report/ (There are 323,285 "extremely low income renter households" in New Jersey and "98,753 affordable and available rental units … That means there is a deficit of 224,531 units.); *See generally* No State Has an Adequate Supply of Affordable Rental Housing for the Lowest Income Renters, National Low Income Housing Coalition (Mar. 2023), https://nlihc.org/gap; Jaboa Lake, Valerie Novack, & Mia Ives-Rublee, Recognizing and Addressing Housing Insecurity for Disabled Renters, Center for American Progress (May 27, 2021), https://www.americanprogress.org/article/recognizing-addressing-housing-insecurity-disabled-renters/.

191. The Age-Friendly Advisory Council is a group of state and local officials as well as representatives from community stakeholder groups, the business sector and the higher education community. The group worked to identify current practices in New Jersey that assist aging individuals, as well as identify barriers that make it difficult for individuals to remain in the community. The group provided recommendations to the Department of Human Services which will issue a blueprint of best practices for advancing age-friendly practices in transportation, housing, inclusivity, and community support and health services.

192. *See* New Jersey Office of Budget and Management, The State of New Jersey Budget in Brief, Fiscal Year 2024, February 2023, at 37 ("DHS plans to spend $13.25 million this year to develop community housing options for individuals currently in nursing facilities and other institutions.")

193. 46.42 C.F.R. § 483.130(m).

194. 47.42 C.F.R. § 483.128.

KEY FINDING THREE ENDNOTES

195. The original list of individuals from DDD included 587 people. Of those people, 23 were in Developmental Centers, or they did not have a facility listed to indicate where they lived. Of the remaining 564 people, 39 were individuals living in pediatric facilities. The 525 individuals left were all adults in traditional long-term care facilities. Ultimately, we met with 357 individuals total, including 31 individuals in pediatric facilities. In total, we met with 326 adults in traditional long-term care facilities.

196. In total, we visited 71 nursing facilities, including one pediatric facility (Voorhees Pediatric). We visited 70 traditional long-term care facilities, including Phoenix Center for Rehabilitation and Pediatrics, which has both adults and pediatric beds. We visited facilities in all 21 counties in New Jersey.

197. Disability Rights New Jersey has provided individual representation to least thirty-nine of these individuals with developmental disabilities in the time since we initially began our investigation. We have included in this report some of the stories of individuals we spoke with, along with some of the successes we have achieved in helping them choose the living arrangement they preferred.

198. *Matter of M.R.*, 135 N.J. 155, 166, 169 (1994). The clear public policy of this State is to respect the right of self-determination of all people, including the developmentally disabled. Respect for that right is implicit in the State Constitution, which recognizes that "[a]ll persons are by nature free and independent, and have certain natural and inalienable rights, among which are those of enjoying and defending life and liberty . . . and of pursuing and obtaining safety and happiness." N.J. Const. art. I, 1. The Legislature, when addressing the rights of developmentally-disabled

citizens in State institutions, declared that the developmentally disabled are entitled to certain fundamental rights as citizens and that these rights shall not be abrogated solely by reason of admission to any facility or receipt of any service for developmentally disabled persons; [and] that services which are offered to the developmentally disabled shall be provided in a manner which respects the dignity, individuality and constitutional, civil and legal rights of each developmentally disabled person . . .. [N.J.S.A. 30:6D-2.] Similarly, the Department of Human Services, in its regulations pertaining to the appointment of guardians, has recognized that "[n]ot every individual with developmental disabilities needs a guardian." N.J.A.C. 10:43-2.1(a). As guardians of personal rights, courts have a special responsibility to protect the right of self-determination. In re Conroy, 98 N.J. 321, 345 (1985). Concerning developmentally disabled citizens, we have declared that the public policy of this State is "to maximize the developmental potential of [developmentally-disabled persons] while affording them the maximum feasible personal liberty." New Jersey Ass'n for Retarded Citizens v. Human Servs., 89 N.J. 234, 252 (1982). In construing the Developmentally Disabled Rights Act, N.J.S.A. 30:6D-1 to -22, we have noted that the Act required the State to provide services to mentally-retarded persons "in 'a setting and manner which is least restrictive of each person's personal liberty.'" Id. at 250 (quoting N.J.S.A. 30:6D-9). Supporting that "requirement is the assumption that handicapped people are autonomous individuals entitled to the same rights and liberties as all other citizens." Ibid.

199. N.J.S.A. 3B: 12-24.1(a). If the court finds that an individual is incapacitated as defined in N.J.S.3B:1-2 and is without capacity to govern himself or manage his affairs, the court may appoint a general guardian who shall exercise all rights and powers of the incapacitated person. The general guardian of the estate shall furnish a bond conditioned as required by the provisions of N.J.S.3B:15-1 et seq., unless the guardian is relieved from doing so by the court.

200. "[A] person who is generally incompetent can still make choices about specific matters," including where the individual resides (*M.R.*, 135 N.J. 155, 165, 169 (1994), *see also Conroy*, 98 N.J. 364, 382 (1985)), guardians have the burden to show "specific incapacity by clear and convincing evidence" *M.R.* 135 NJ at 169; *Conroy,* 98 N.J. at 365.

A person subject to general guardianship that is silent on capacity related to individual rights retains that decision-making authority for each individual right, absent a showing by the challenger that the individual is not capable of having the capacity to make their own choice. *Matter of M.R.,* 135 N.J. 155, 638 A.2d 1274 (1994) (court-appointed counsel must report as to "a delineation of those areas of decision-making that the alleged mentally incapacitated person may be capable of exercising"; *In re Guardianship of Macak*, 377 N.J. Super. 167, 181, 871 A.2d 767, 775 (App. Div. 2005) (right to choose where to live; "In this case, Mr. Macak has consistently expressed a strong preference to live in his own house. Of course, if Mr. Macak is not incapacitated, he has a right to choose to live at home, even if that seems to his family and friends to be an impractical or risky choice."); *In re Absentee Ballots Cast by Five Residents of Trenton Psychiatric Hosp.*, 331 N.J. Super. 31, 38, 750 A.2d 790, 794 (App. Div. 2000) (voting rights).

201. *Matter of M.R.*, 135 N.J. 155, 167 (1994).

202. *Matter of M.R.*, 135 N.J. 155, 167 (1994); R. 4:86(a)(8). If the alleged incapacitated person is not represented by counsel, the order shall include the appointment by the court of counsel for the alleged incapacitated person.

203. *Matter of M.R.*, 135 N.J. 155, 167 (1994).

204. *See generally* PASRR Technical Assistance Center, PASRR Learning Module 4: Person-Centered PASRR (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-4%3A-Person-Centered-PASRR.

205. *See generally* PASRR Technical Assistance Center, PASRR Learning Module 4: Person-Centered PASRR, at 11 (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-4%3A-Person-Centered-PASRR.

206. The Learning Community for Person Centered Practices, https://tlcpcp.com/ (last visited Aug. 23, 2023); *See generally* PASRR Technical Assistance Center, PASRR Learning Module 4: Person-Centered PASRR, at 13 (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-4%3A-Person-Centered-PASRR.

207. The Learning Community for Person Centered Practices, https://tlcpcp.com/ (last visited Sept. 5, 2023).

208. In New Jersey, the Long Term Supports and Services systems have gone through two main channels: a) Section 1915(c) waivers; and b) Section 1115 "Demonstration" waivers. The statutory basis for Section 1915(c) waivers is found at 42 U.S.C. 1396n. The statutory basis for Section 1115 waivers is found at 42 U.S.C. § 1315. New Jersey had historically used 1915(c) waivers to deliver services, and had four waivers under 1915(c) until 2014. However, all but one of New Jersey's Home and Community-Based Services 1915(c) waivers have been incorporated into their 1115 Demonstration waiver, NJ Family Care Comprehensive Waiver. N.J. Division of Medical Assistance & Health Services, NJ FamilyCare Comprehensive Demonstration, https://www.state.nj.us/humanservices/dmahs/home/waiver.html (last visited Aug. 23, 2023). The NJ Community Care Waiver was formerly a 1915(c) waiver but was folded into the 1115 Demonstration waiver.

209. Long Term Services and Supports (LTSS) refers to long-term care services provided through NJ's Medicaid FamilyCare program. Long-Term Services and Supports provides services whether a recipient resides in an institutional setting like a nursing facility, an assisted living facility, or in a home-and-community-based setting.

210. The Nursing Home Reform Act was passed as part of the Omnibus Budget Reconciliation Act of 1987. Its Medicaid provision was codified as 42 U.S.C. § 1396r(b)(4), while its Medicare provision was codified as 42 U.S.C. § 1395i-3(b)(4). The federal regulations that provide guidance regarding the Nursing Home Reform Act can be found at 42 C.F.R. § 483.25.

211. The PASRR regulations were ahead of the curve in 1992, because they incorporated principals of person-centered practices. See PASRR Technical Assistance Center, PASRR Learning Module 4: Person-Centered PASRR (Oct. 6, 2016), https://www.pasrrassist.org/pasrr101/PASRR-Learning-Module-4%3A-Person-Centered-PASRR

212. Medicaid Program; State Plan Home and Community-Based Services, 79 Fed. Reg. 2947, 3004 (Jan. 16, 2014) (to be codified at 42 C.F.R. § 430). 42 C.F.R. § 440.180. See also 42 C.F.R. 483.10, 42 C.F.R. 483.21, A Closer Look at the Revised Nursing Facility Regulations, The National Consumer Voice for Quality Long Term Care, (Nov. 28, 2016), https://theconsumervoice.org/uploads/files/issues/A_Guide_to_the_Revised_Nursing_Facility_Regulations.pdf.

213. 42 C.F.R. § 441.301(c)(1). The rule requires that service planning for participants in Medicaid HCBS programs under section 1915(c) and 1915(i) of the Act must be developed through a person-centered planning process that provides necessary information and support to ensure that the individual directs the process to the maximum extent possible and is enabled to make informed choices and decisions.

214. Medicaid Program; State Plan Home and Community-Based Services, 79 Fed. Reg. 2947, 3004 (Jan. 16, 2014) (to be codified at 42 C.F.R. § 430).

215. 42 C.F.R. § 441.301(c)(1) through 441.301(c)(3); *See also* Gwen Orlowski & Julie Carter, A Right to Person-Centered Care Planning, Justice In Aging (April 2015), http://justiceinaging.org/wp-content/uploads/2015/04/FINAL_Person-Centered_Apr2015.pdf.

216. 42 C.F.R. § 441.301(c)(1).

217. 42 C.F.R. § 441.301(c)(4). CMS requires informed choices that relevant to the needs and preferences of the specific consumer, as they note that it can be difficult for providers to strike a balance between too much and too little information to give in order for the individual's choice to be informed. Person-Centered Planning Process, 79 Fed. Reg. 3007 (Jan. 16, 2014).

Throughout CMS person-centered regulations including the HCBS rule and the PASRR regulations, CMS incorporates requirements that state include housing alternatives even if they are not currently available - the purpose of this is to assist states as they build out accessible, affordable housing, especially for people with disabilities and older adults.

218. 42 C.F.R. § 441.301(c)(2)(ii-iv).

219. 42 C.F.R. § 441.301(c)(2)(i).

220. 42 C.F.R. § 441.301(c)(2)(vii and ix).

221. 42 C.F.R. § 441.301(c)(3). Individuals also have a Constitutionally protected due process right to appeal services within the plan any time there is an adverse action (e.g. denial, reduction, termination, authorization for less than what was requested. 42 C.F.R. § 431.220; 42 C.F.R. § 438, Subpart F.

222. *See* Gwen Orlowski & Julie Carter, A Right to Person-Centered Care Planning, Justice In Aging (April 2015), http://justiceinaging.org/wp-content/uploads/2015/04/FINAL_Person-Centered_Apr2015.pdf.

223. 42 C.F.R. § 441.301(c)(2).

224. Person-Centered Planning Process, 79 Fed. Reg. 3008 (January 16, 2014). See also, 42 C.F.R. 441.301(c)(2)(xiii). Modification must be supported by a specific assessed need, and it must be justified.

225. Person-Centered Planning Process, 79 Fed. Reg. 3008 (January 16, 2014). See also, 42 C.F.R. 441.301(c)(2)(xiiii).

226. Medicare & Medicaid Programs; Reform of Requirements for Long- Term Care Facilities, 81 Fed. Reg. 68688 (Oct. 4, 2016) (amending CFR Parts 405, 431, 447, 482, 483, 485, 488, and 489).

See also, 42 C.F.R. 482.43. "The hospital must have an effective discharge planning process that focuses on the patient's goals and treatment preferences and includes the patient and his or her caregivers/support person(s) as active partners in the discharge planning for post-discharge care. The discharge planning process and the discharge plan must be consistent with the patient's goals for care and his or her treatment preferences, ensure an effective transition of the patient from hospital to post-discharge care, and reduce the factors leading to preventable hospital readmissions."

227. Federal Requirements of Participation for Nursing Homes: Summary of Key Changes to the Rule – Part III, National Consumer Voice for Quality Long-Term Care (Sept. 2016), https://theconsumervoice.org/uploads/files/issues/summary-of-key-changes-effective-phase-3_final.pdf; See also Eric Carlson, Lori Smetanka, & Nancy Stone, Advocating for Nursing Facility Residents Under the Revised Federal Requirements, 14 National Academy of Elder Law Attorneys 6-8 (Spring 2018).

228. 42 C.F.R. § 483.10(a)

229. 42 C.F.R. § 483.10(c)(2)

230. 42 C.F.R. § 483.21(c)(2)(ii)

231. 42 C.F.R. § 483.10(f)

232. *Matter of M.R.*, 135 N.J. 155, 638 A.2d 1274 (1994) (An individual retains decision-making authority for each individual right, absent a showing by the challenger that the individual is not capable of having the capacity to make their own choice, and court-appointed counsel must report as to "a delineation of those areas of decision-making that the alleged mentally incapacitated person may be capable of exercising").

233. 42 C.F.R. § 483.21

234. 42 C.F.R. § 483.10; *See generally* Federal Requirements of Participation for Nursing Homes: Summary of Key Changes in the Rule, The National Consumer Voice for Quality Long-Term Care (Sept. 2016), https://theconsumervoice.org/uploads/files/issues/summary-of-key-changes-effective-phase-1-final.pdf

235. 42 C.F.R. § 483.10; *See generally* Federal Requirements of Participation for Nursing Homes: Summary of Key Changes in the Rule, The National Consumer Voice for Quality Long-Term Care (Sept. 2016), https://theconsumervoice.org/uploads/files/issues/summary-of-key-changes-effective-phase-1-final.pdf

236. 42 C.F.R. § 441.301(c)(1-3), 441.725; N.J.A.C. § 8:85-2.1; N.J.A.C. § 10:53-2.1. 42 C.F.R. § 483.10; See generally Federal Requirements of Participation for Nursing Homes: Summary of Key Changes in the Rule, The National Consumer Voice for Quality Long-Term Care (Sept. 2016), https://theconsumervoice.org/uploads/files/issues/summary-of-key-changes-effective-phase-1-final.pdf

237. During our Woodland's investigation, we observed a resident of the facility's infamous third floor who could not use the elevator to go to a vending machine on a different floor to make a purchase when the vending machine on the third floor was broken because the elevator had a guard stationed to prevent third floor residents from leaving.

238. N.J.S.A. 30:13-1 through 30:13-19. Some stakeholders recall that the New Jersey law influenced the later passing of the federal Nursing Home Reform Act of 1987.

239. N.J.A.C. § 8:39-4.1; N.J.A.C. § 8:85-1.17 Residents Rights: The nursing facility shall ensure that each resident and his or her representative are informed of their rights upon admission and provided with a written statement of all resident rights, in accordance with 42 CFR 483.10 through 483.15, the Nursing Home Resident Rights Act, N.J.S.A. 30:13-1 et seq. and N.J.A.C. 8:39-4.1.

240. N.J.S.A. 30:14-3(g) and N.J.A.C. 8:394.1(a)(35). On the other hand, the regulations recognize the role of the LTC Ombudsman, but not the Protection and Advocacy, as required by federal law.

241. N.J.S.A. § 30:13-5; N.J.A.C. § 5:19-9.2 (regulations implementing the N.J.S.A. § 30:13-5)

242. *Compare* 42 C.F.R. § 483.21, with N.J.S.A. § 30:13-5(i) and (j), and N.J.A.C. § 8:39-11.1, N.J.A.C. § 8:39-11.2, N.J.A.C. § 8:39-12.1 (which include no requirement that the patient participate in the creation of their interdisciplinary care plan.)

243. 42 C.F.R. § 483.10(f) ("The resident has the right to and the facility must promote and facilitate resident self-determination through support of resident choice.")

244. *Compare* 42 C.F.R. § 483.10(f)(4) ("The resident has a right to receive visitors of his or her choosing at the time of his or her choosing, subject to the resident's right to deny visitation when applicable, and in a manner that does not impose on the rights of another resident self-determination."), with N.J.A.C. § 8:39-4.1(23) (Residents have the right "(t)o meet with any visitors of the resident's choice between 8:00 A.M. and 8:00 P.M. daily. If the resident is critically ill, he or she may receive visits at any time from next of kin or a guardian, unless a physician or advanced practice nurse documents that this would be harmful to the resident's health").

245. Under the 2016 revised federal rules, a nursing home resident may only be lawfully discharged for one of six reasons: 1. The nursing home cannot meet the resident's needs; 2. The resident no longer needs nursing facility services; 3. The resident's presence endangers the safety of others; 4. The resident's presence endangers the health of others; 5. The resident has failed to pay (subject to review for Medicaid eligibility); or 6. The facility is closing. 42 C.F.R. § 483.15(c)(1)(i); See also National Consumer Voice for Quality Long-Term Care, Center for Medicare Advocacy, & Justice in Aging, A Closer Look at the Revised Nursing Facility Regulations: Involuntary Transfer and Discharge, https://www.justiceinaging.org/wp-content/uploads/2017/01/Revised-Nursing-Facility-Regulations_Involuntary-Transfer-and-Discharge.pdf.

In addition, federal law ensures procedural rights and due process: written notice that contains certain information must be provided in a timely manner (42 C.F.R. § 431.210 and 431.211) and residents have the right to appeal through a fair hearing (42 C.F.R. § 431.220).

The New Jersey statutory provisions regarding discharge and transfer, N.J.S.A. § 30:13-6, originally enacted in 1976 before the 1987 federal NHRA, and the State's involuntary discharge (N.J.A.C. § 8:39-4.1(31) and (32)) and transfer (N.J.A.C. 8:85-1.10) regulations do not meet the standards set forth in the federal law. For example, state regulations do not afford federally guaranteed due process appeal rights and a fair hearing for discharges. Involuntary transfer protections only apply to Medicaid recipients or those with pending Medicaid applications (N.J.S.A. § 30:13-6). State regulations do not clearly limit involuntary discharge/transfers to the six allowable reasons under federal law. N.J.A.C. § 8:39-4.1(31).

Through our representation of clients, Disability Rights NJ sees many instances where nursing home residents are involuntarily transferred or discharged without even the New Jersey requirements being met, let alone the federal ones. The robust protection of nursing home residents, including those with IDD, requires that the Legislature and Departments of Human Services and Health amend the New Jersey involuntary discharge and transfer laws to ensure residents have the full measure of federal rights and protection.

246. 42 C.F.R. § 483.15(3) ("The facility must not request or require a third party guarantee of payment to the facility as a condition of admission or expedited admission, or continued stay in the facility.")

247. 42 C.F.R. § 483.21(c) ("The facility must develop and implement an effective discharge planning process that focuses on the resident's discharge goals, the preparation of residents to be active partners and effectively transition them to post-discharge care, and the reduction of factors leading to preventable readmissions.")

248. N.J.S.A. § 30:13-4.2; N.J.S.A. § 30:13-8

249. DOH conducts about 500 inspections of nursing facilities each year and typically responds to 1,000 complaints annually. Nursing facilities are inspected without prior notice over a three to four-day period. Inspection teams focus on the consistency and comprehensiveness of patient care, patient rights, staffing levels, and infection control procedures. The surveyors conduct an unaccompanied facility tour, and request information such as the census number and the list of residents, recent admissions, the schedules of medication administration, and the schedules of licensed, registered nursing staff. They also review other quality of life measures such as dietary services and housekeeping. When the inspectors inform a facility of a deficiency, the facility must, within 10 business days, submit a written plan of correction. If the deficiency is serious, DOH may also issue a penalty. See License Surveys/Inspections, New Jersey Department of Health, https://www.nj.gov/health/healthfacilities/surveys-insp/ (last visited Sept. 8, 2023).

250. New Jersey Long-Term Care Ombudsman, Resident Rights Citation Rate by State Citations issued between Jan. 2, 2022 and September 28, 2022 (Nov. 17, 2022) (extracted from data.cms.gov for the time period January 2, 2022 to September 28, 2022).

251. We found that culturally the DDD system is more attuned to person-centered thinking, and so the practices are more robust, though could always be improved upon. That pervasive culture of person-centered thinking is less evident in MCO managed MLTSS - our anecdotal observations and input from stakeholders paints a picture of formulistic service planning by MCO care managers that give short shrift to a person's lead of the process, goals, preferences and desires to include non-Medicaid services in services plans are required by the 2014 federal HCBS Rule.

252. MCOs in New Jersey have failed to correctly assess for functional need, failed to adequately determine how those needs will be met, and failed to ensure that they are met in actuality. *See* U.S. Department of Health & Human Services, Office of Inspector General, Report No. A-02-17-01018, New Jersey Did Not Ensure That Its Managed Care Organizations Adequately Assessed and Covered Medicaid Beneficiaries' Needs for Long-Term Services and Supports (June 2020), https://oig.hhs.gov/oas/reports/region2/21701018.pdf. ("MCOs did not comply with the requirements to adequately assess and cover the associated beneficiaries' needs for long-term services and supports. Specifically, MCOs did not comply with requirements for (1) providing adequate service planning and care management to the beneficiaries and (2) conducting and documenting assessments; and developing, reviewing, and updating beneficiaries' care plans. These deficiencies occurred because New Jersey did not adequately monitor MCOs for compliance with certain Federal and State requirements."). *See also* Gwen Orlowski & Julie Carter, *A Right to Person-Centered Care Planning*, Justice In Aging (April 2015), http://justiceinaging.org/wp-content/uploads/2015/04/FINAL_Person-Centered_Apr2015.pdf ("The rule embodies the growing recognition that assessments of functional need may be a necessary and important part of service plan development, but that the PCP process should yield 'quality-of-life goals that exceed the ability of any set of program-specific services and supports to meet them.' The purpose is to encourage the development of written plans that include goals and outcomes that are not defined exclusively by covered Medicaid services, and to find innovative ways to meet these broader goals and desired outcomes.")

253. 42 U.S.C. § 1315. *See also* About Section 1115 Demonstrations, Medicaid.gov, https://www.medicaid.gov/medicaid/section-1115-demonstrations/about-section-1115-demonstrations/index.html (last visited Sept. 8, 2023).

254. Centers for Medicare & Medicaid Services, New Jersey FamilyCare Comprehensive Demonstration - Special Terms and Conditions, https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf

255. Centers for Medicare & Medicaid Services, New Jersey FamilyCare Comprehensive Demonstration - Special Terms and Conditions 9.6(h), https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf.

256. Centers for Medicare & Medicaid Services, New Jersey FamilyCare Comprehensive Demonstration - Special Terms and Conditions 10.2(a)(v)(1), https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf ("The state may cover . . . (h)ousing transition navigation services, including . . . (a)ssistance with the set-up of the new housing unit, to address needs identified in the person-centered care plan, including clinically appropriate residential modifications to allow the beneficiary to move in and identified needs for assistance with arranging the move and supporting the details of the move, as appropriate.")

257. New Jersey Department of Human Services, Division of Medical Assistance & Health Services, State Plan Under Title XIX of the Social Security Act Medical Assistance Program, Attachment 3: Services, Including Scope and Limitations 378, https://www.state.nj.us/humanservices/dmahs/info/state_plan/Attachment3_Services_including_Scope_and_Limitations.pdf (Personal Care Assistant services); Id. at 555 (Adult Day Health – called Medical Day Care in the State Plan); N.J.A.C. § 10:60 (Personal Care Assistant Services); N.J.A.C. § 10:164 (Adult Day Health Services).

258. Centers for Medicare & Medicaid Services, New Jersey FamilyCare Comprehensive Demonstration - Special Terms and Conditions 5.6, https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf.

259. Centers for Medicare & Medicaid Services, New Jersey FamilyCare Comprehensive Demonstration - Special Terms and Conditions 5.8 https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf.

260. Centers for Medicare & Medicaid Services, New Jersey FamilyCare Comprehensive Demonstration - Special Terms and Conditions 5.11, https://www.medicaid.gov/sites/default/files/2023-03/nj-1115-cms-exten-demnstr-aprvl-03302023.pdf.

261. N.J.A.C. § 10:44A-1.3. ("Person-centered planning" means a process of helping individuals, in accordance with their needs and preferences, to achieve a lifestyle that is consistent with the norms and patterns of general society and in ways which incorporate the principles of age appropriateness and least restrictive interventions.")

262. 55 N.J. Reg. 175 (Feb. 6, 2023).

263. N.J. Department of Human Services, Division of Developmental Disabilities, Supports Program Policies & Procedures Manual 14 (Aug. 2023), https://www.nj.gov/humanservices/ddd/assets/documents/supports-program-policy-manual.pdf (last visited Aug. 24, 2023). The Division of Developmental Disabilities (DDD) is a Division within the Department of Human Services which helps connect individuals with developmental disabilities to services and supports providers, and administers two waiver programs, the Supports Program and the Community Care program. DDD also operates the five Intermediate Care Facility Developmental Centers across the state. Division of Developmental Disabilities, https://www.state.nj.us/humanservices/ddd/ (last visited Aug. 25, 2023).

264. N.J. Department of Human Services, Division of Developmental Disabilities, Supports Program Policies & Procedures Manual 23 (Aug. 2023), https://www.nj.gov/humanservices/ddd/assets/documents/supports-program-policy-manual.pdf (last visited Aug. 24, 2023).

265. N.J. Department of Human Services, Division of Developmental Disabilities, Supports Program Policies & Procedures Manual 31 (Aug. 2023), https://www.nj.gov/humanservices/ddd/assets/documents/supports-program-policy-manual.pdf (last visited Aug. 24, 2023).

266. N.J. Department of Human Services, Division of Developmental Disabilities, Supports Program Policies & Procedures Manual 36 (Aug. 2023), https://www.nj.gov/humanservices/ddd/assets/documents/supports-program-policy-manual.pdf (last visited Aug. 25, 2023).

267. N.J. Department of Human Services, Division of Developmental Disabilities, *Supports Program Policies & Procedures Manual* 40, 183 (Aug. 2023), https://www.nj.gov/humanservices/ddd/assets/documents/supports-program-policy-manual.pdf (last visited Aug. 24, 2023).

268. The Boggs Center on Developmental Disabilities, Developing Effective Person-Centered Planning Tools & New Jersey Individualized Service Plans (Dec. 2021), https://boggscenter.rwjms.rutgers.edu/documents/BOGGS/Publications/SupportCoordination/DevelopingEffectivePCPTNJISP-ENG.pdf (last visited Aug. 24, 2023).

269. The Boggs Center on Developmental Disabilities, Developing Effective Person-Centered Planning Tools & New Jersey Individualized Service Plans 3 (Dec. 2021), https://boggscenter.rwjms.rutgers.edu/documents/BOGGS/Publications/SupportCoordination/DevelopingEffectivePCPTNJISP-ENG.pdf (last visited Aug. 24, 2023).

270. Section Q of the MDS (Centers for Medicaid and Medicare Services, Long-Term Care Resident Assessment Instrument User's Manual, Version 1.1.8.11, Draft Version effective October 1, 2023, available at https://www.cms.gov/files/document/draftmds-30-rai-manual-v11811october2023.pdf-0, at Q-1,)

271. MFP, first authorized by the Deficit Reduction Act of 2005 (Pub. L. 109-171 (2006) 120 Stat. 4) is a demonstration that provides federal funds to states to support Medicaid beneficiaries in transitioning from institutions to the community. Medicaid.gov, Money Follows the Person, https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html (accessed Sept. 28, 2023).

Data from "MFP Transition" chart graciously provided by Terre Lewis, NJ MFP Project Director, Dept. of Human Services, Division of Developmental Disabilities, New Jersey on September 27, 2023.

See also AARP, https://ltsschoices.aarp.org/scorecard-report/innovation-and-opportunity (last visited Sept. 28, 2023). AARP's scorecard is a collection of data from states related to long-term services and supports for older adults, people with physical disabilities, and family caregivers.

272. Lilo H. Stainton, Thousands of NJ families frustrated by long wait for disability services, NJ Spotlight News, (Aug. 21, 2023), https://www.njspotlightnews.org/2023/08/thousands-nj-families-frustrated-with-long-wait-for-adequate-disability-services/; P. Kenneth Burns, How New Jersey is feeling the impact of the affordable housing shortage, WHYY PBS (Apr. 7, 2023), https://whyy.org/articles/new-jersey-affordable-housing-shortage-report/ (There are 323,285 "extremely low income renter households" in New Jersey and "98,753 affordable and available rental units … That means there is a deficit of 224,531 units.); See generally No State Has an Adequate Supply of Affordable Rental Housing for the Lowest Income Renters, National Low Income Housing Coalition (Mar. 2023), https://nlihc.org/gap; Jaboa Lake, Valerie Novack, & Mia Ives-Rublee, Center for American Progress, Recognizing and Addressing Housing Insecurity for Disabled Renters (May 27, 2021), https://www.americanprogress.org/article/recognizing-addressing-housing-insecurity-disabled-renters/.

273. DMAHS reported that these Healthy Homes "will support better health outcomes for individuals at risk of homelessness or institutionalization," and that "Operating funds will ensure that the housing remains affordable and dedicated to Medicaid beneficiaries for the 30- year life of the unit." Letter from Jennifer Langer Jacobs, Ass't Commissioner, Division of Medical Assistance and Health Services, to Daniel Tsai, Deputy Administrator and Director, Center for Medicaid & CHIP Services 8-9 (June 12, 2021), https://nj.gov/humanservices/assets/slices/NJHCBSspending.pdf (New Jersey's "Estimated Total Investment (State+Federal)" in the Healthy Homes initiative was $53 million dollars, of which all $53 million was the "Estimated State Share").

See also New Jersey Department of Human Services, Meeting of the Medical Assistance Advisory Council Presentation 44 (Feb. 21, 2023), https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Meeting_Presentations_2-1-23.pdf.

274. Lilo H. Stainton, Murphy budgets $100M to keep people at home, out of nursing homes, NJ Spotlight News (May 1, 2023), https://www.njspotlightnews.org/2023/05/murphy-budgets-100m-to-keep-people-at-home-out-of-nursing-homes/ ("Under this initiative, which officials said is still being developed, nursing home residents who have an intellectual or developmental disability or diagnosis of serious mental illness would be eligible to transfer to a group home or private residence, with support services. Funding could also be used to expand capacity at group homes or other community residential sites, officials said.").

See also Alliance for the Betterment of Citizens with Disabilities, FY24 State Budget Signed Into Law (July 13, 2023), https://www.abcdnj.org/fy24-state-budget-signed-into-law/ (The budget included "a total of $5 million in one-time funds to support the development of the location, furniture, vehicles, accessibility, staff training and other expenses" for the 25 group homes).

The budget included a $21.4 million increase, centrally budgeted in the CCP – Individual Supports budget line, which will in part fund housing options for nursing facility residents who wish to transition to community settings. New Jersey Legislature, Office of Legislative Services, Fiscal Year 2023-2024 Analysis of the New Jersey Budget Department of Human Services (Apr. 2023), https://pub.njleg.state.nj.us/publications/budget/governors-budget/2024/DHS_analysis_2024.pdf.

See also Alliance for the Betterment of Citizens with Disabilities, FY24 State Budget Signed Into Law (July 13, 2023), https://www.abcdnj.org/fy24-state-budget-signed-into-law/ (The budget included "a total of $5 million in one-time funds to support the development of the location, furniture, vehicles, accessibility, staff training and other expenses" for the 25 group homes).

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