I Choose Home NJ Annual Report

From Institution to Community Living 2015



www.IChooseHome.nj.gov

Created by I Choose Home NJ New Jersey's Money Follows the Person Program

Chris Christie, Governor Kim Guadagno, Lt. Governor



A Message from the Statewide Program Director

Welcome to ICHNJ!

This is an exciting time for the I Choose Home NJ Program and we are thrilled to share this First ICHNJ Program Report with you. This report gives an overview and history of the ICHNJ program with a special emphasis on recent (2014) feedback and stories from our participants.

The I Choose Home NJ program is about helping individuals leave nursing homes and developmental centers and re-enter community life with the supports and services they need to thrive. At the same time, the program is designed to build more services and supports for everyone – so that more people can age in place and remain in their communities. This report highlights our successes on both fronts.



Terre Lewis Statewide MFP Program Director

Although the I Choose Home NJ program was created in 2008, much of our work and growth has occurred since 2011, when we reached full staffing levels and began transitioning greater numbers of individuals. Since its inception, we have helped move more than 1,600 people from New Jersey nursing homes and developmental centers back to the community. Program data shows that these individuals are happier in the community than they were in the nursing home or developmental center and that they feel just as safe and well cared for, often more so, than when they lived in an institution. Perhaps most importantly, participants feel that they have more autonomy and freedom to live their lives on their terms.

By transitioning more than 1,600 individuals, I Choose Home NJ has saved New Jersey more than \$20 million. These funds have been re-invested in a variety of creative and innovative ways to increase long-term care services for all New Jerseyans. This Report explores each of these initiatives in more depth. In addition to the strong partnership we enjoy among the Department of Human Services' Division of Aging Services, Division of Developmental Disabilities and Division of Disability Services and the NJ Elder Ombudsman's Office, we have worked hard to tighten connections with important stakeholders and other community partners.

Our Partnership Group, formed in 2011, now boasts 34 members from all walks of life. Increased input and collaboration from this group has resulted in concrete action, such as a recent agreement by one of our housing developer partners to set aside four accessible and affordable apartments in his new housing development.

The future for home- and community-based services in New Jersey is bright, but not without its challenges. We are moving toward a world with more choices for people who want to live and age in their communities, without the immediate need to go into an institutional setting. I Choose Home NJ is proud to be a part of that effort – not only in moving individuals home, but in envisioning and summoning up the resources that are needed to change the system for all and for always.

We invite you to explore the following pages to see how older adults and people with disabilities are living and thriving through the I Choose Home NJ program.

Perre Lewis

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I Choose Home – NJ (also known as Money Follows the Person) is a federal/ state program with two main goals:

- to move people out of nursing homes and developmental centers into the community with the in-home services they need; and
- to re-invest Medicaid dollars saved into home and community-based services to grow the system.

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The data graphics contained in this report reflect the results of the 2014 Quality of Life Survey, administered to ICHNJ participants between 1/1/2014 and 12/31/2014.



All across the country, states are moving to of t "rebalance" their long-term care systems to create peo

more opportunities for people to live independently in their communities for as long as possible, as opposed to in institutional settings like nursing homes or developmental centers.

Court settlements requiring states to move people with disabilities and/or mental illness out of institutions, new federal rules about where long-term care Medicaid dollars can be spent, the recent move to private management of long-term care Medicaid systems, and federal programs to incentivize states to keep consumers out of institutions are all aligning to create more opportunities for people to age in place.

In New Jersey, we are starting to see evidence of the sea change towards more community-based Medicaid services. Since 2009, the percentage of total long-term care Medicaid expenditures for people receiving services in community settings increased from 20% to about 35%. While there is still progress to be made towards a truly balanced long-term care system, the needle is clearly moving.

The I Choose Home NJ (called Money Follows the Person at the federal level) is an integral part of this national and statewide movement toward community-based care. Forty-four states and Washington, D.C. now participate in this federal initiative. In moving people out of nursing homes and developmental centers and back into the larger community, New Jersey accrues a Medicaid savings that we are investing into more home- and community-based services for all New Jersey residents.

"A Nursing Home May Not Be the Only Option."



All of our participants have lived in a nursing home or developmental center for at least 90 days, are eligible for Medicaid at least one day prior to moving out, are moving to an independent setting as defined by federal requirements (either back home or to a new apartment, etc.), and truly want to leave.

For the first year that the I Choose Home NJ consumer returns to the community, New Jersey receives an enhanced Medicaid match from the federal government. Normally, New Jersey pays 50% of the Medicaid expense and the federal government pays the other 50%. Under ICH, the federal government pays 75%, generating a 25% savings called "rebalancing funds." These funds must be reinvested to expand home- and community-based services and infrastructure, so that more New Jerseyans can age in place with the services they need. New Jersey's I Choose Home NJ team has successfully transitioned 1,600+ people from institutions back into home- and community-based settings for a savings of over \$20 million. Our goal is to transition more than 2,200 people through 2020. This will ultimately result in a savings of \$35.5 million dollars, to be spent on much-needed home and community based services for New Jersey's elderly and disabled populations.

The I Choose Home NJ program has been a learning experience for all involved. It has required participation and collaboration among two State agencies and several agency divisions, consumers, health care professionals, managed care organizations, housing specialists, employment professionals, attorneys, and many others. It has also required an incredible amount of creativity and determination to overcome systemic and situational barriers for our participants.

"A Developmental Center May Not Be the Only Option."



85%

like their home.

Our Success Stories

The following pages highlight some of our favorite success stories as well as important feedback from all of our program participants.

As you can see, these stories highlight something very important: there is no "typical" or "ideal" candidate when it comes to moving out of an institution back into the community.

Despite very different individual circumstances, the I Choose Home NJ team has been able to make successful transitions happen for hundreds of people.

We have helped transition people over the age of ninety (90), couples who met and fell in love while living in an institution, young people with disabilities, people with extensive family support,

> people with no one else to help them, and everyone in between.

In addition, the feedback we receive - by surveying individuals one year and two of people that moved years after they have transitioned into the community home - is overwhelmingly positive. People report greater independence and freedom and say that the services they get at home are just as comprehensive, if not more, than in the nursing home or developmental center.

IChooseHome.nj.gov

As long as I can, I will be home.

- Mary

ICHNJ Helps Mary Keep her Family and Puppy Close

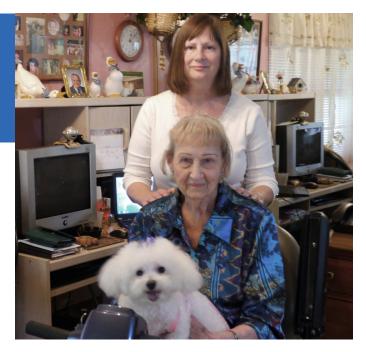
They say wisdom comes with age and, one could argue, so does resolve.

When 91-year- old Mary Woodburn landed in a rehabilitation and nursing facility after a slip and fall, she was determined to return home after her recovery.

Living alone and with limited mobility, seniors like Mary often wind up in a nursing home to receive supports and services rather than remaining in their own home with the help they need. But in recent years, thanks to a federal initiative called Money Follows the Person (MFP), there has been a shift towards home- and community-based services for older adults and people with disabilities. Rebranded as I Choose Home NJ in the Garden State, Mary is one of thousands of elderly and disabled individuals who are taking advantage of this opportunity to move out of long-term care settings and into the community, while still getting proper care.

"I have my girls that come in and help me every day with the things I can't do," the South Carolina native said. "They help me with everything – the house, bathing, they fix my dinner. They're like my family and they're so close to me. I even said this morning, 'I don't know what I'd do without you. You're my right hand.' And I really mean that."

And Mary is thriving. From spending time with family to enjoying the company of her puppy, to connecting with friends on Facebook, she enjoys the freedom to be able to do things without a set schedule.



"I was so glad to get home. You're around all the things you love. Your kids can run in and out to come see you... easier than a nursing home. I don't ever want to go to a nursing home. As long as I can, I will be here," the breast cancer survivor said.

The help also comes as a relief to her loved ones.

"It's been a lot easier on the family and on me, having the help of aides because we know she's okay. There's somebody everyday with her and if she needs something, they'll help her with that," her niece Judy explained.

Mary hopes her story will encourage more nursing home residents to consider I Choose Home NJ as an option.

"I would tell them to come out of there and go to their home, and get some help from the home helpers. That's what I did," she said. "And some people don't know they can do this. But by me doing this, I hope that it will convince people there is a way."

Mary passed away on January 1, 2015, but lived her final months at home as she wanted. ICHNJ is grateful for Mary agreeing to share her story.



[I Choose Home NJ] gives us a chance to live our lives as the person that we are meant to be.

- Anthony

Three's Company Through I Choose Home NJ

Combined, Anthony, Carla, and Richard spent more than 17 years living in a nursing home. And according to Anthony, life in a long-term care facility left something to be desired. Recently married, Anthony and Carla craved the freedom to go about their day without any rules or regulations.

All wheelchair users, the three needed help with "activities of daily living," but believed there was another way to live independently while still getting the care they needed.

"At the nursing home, every day we had to write down the time when we wanted to get up and why. That goes for bed time too. They took the reason to decide who gets up first," Carla explained.

Now they can get up and go to bed when they want to. Anthony and Carla can share the same room.

"In the morning, our helpers ask us if we want to get up, and one of us might say not right now. And they let us do that. In the nursing home, they have a schedule. If we didn't get up, they'd say, 'then we'd have to get you after lunch," Anthony recalled.

The only bright spot to the nursing home was that it was the place where Anthony met Carla, and where he found a best friend in Richard. It's a bond so strong that Anthony sees him as a father-figure.

"Tony suggested instead of me moving into an apartment, that we try and develop a group home together and that's how we ended up here," Richard said.

With a spacious backyard and 24-hour in-home services, their house, designed with their needs in mind factor like home.



mind, feels like home.

"Being on my own, it feels fantastic. It's better than staying in one building with a whole bunch of people that you don't know. And when you get to go out and be a part of the community, you're living life," Anthony said. "You're being the normal person that we all know you are."

"We go out if we want. We just tell [the aides] the day before or the

morning of. We can go to family things and not leave early," Carla added.

For Richard, his home represents the type of living environment he has envisioned for a very long time.

"For a very big chunk of my adult life, I had a vision that disabled people could live together in small groups in the community," said Richard. "This is the proof of a vision that I've had that goes back for years." We're our own boss. We pick our destiny. We pick and choose what we want to do for that day, and that's how we live life.



Couple Finds Love in Nursing Home, Begins Happy Ending in the Community

When Donna saw Steven across the hall, there was an instant attraction. The hall, however, was the hallway of a nursing facility where she had lived for the past two years, and both landed there as a result of health emergencies.

- Steve

"I said to my roommate Eleanor, 'Wow, I'd like to spend some time with him'. She said, 'don't even think about it. He's my boyfriend," Donna laughed. But being the friend that she was, Eleanor made introductions and the rest is history.

On many occasions, Steven and Donna would talk about plans for a future together. And when Donna proposed one quiet evening, they knew that growing old together in a nursing home was not the future they envisioned.

"We decided we needed to get a little healthier, a little stronger, and get up out of there where we could both be happy together," Steven said. They wanted the privacy and freedom that the nursing home could not provide. Despite plans of marriage, the facility could not accommodate several of their requests, including rooming together.

"There weren't many activities there. I would say that the three main activities of the day were breakfast, lunch and dinner," said Steven. "The backup activities were waiting for the food to come. I used to make a joke about it." After a visit from an I Choose Home NJ representative, the couple learned that they were eligible to transition out of the nursing home and into the community. Because neither Steven nor Donna had a home to return to, ICHNJ had the responsibility of first locating a place for them to live that met their needs. A year and a half later, they found their home in Ewing, in an independent living apartment.

"We came to visit and I was really happy, immediately. As soon as I walked into the building and saw how fresh and clean it smelled, I said it would make me and Donna very happy," Steven recalled.

They made their decision and have never looked back. Little things, like the opportunity to go to the mall or grocery shopping are pleasures they now get to experience on a regular basis.

"At the nursing home, we had rooms and even though it had a door, people could just walk in. Plus you had a roommate. It wasn't your own dwelling. This is ours. We could do whatever we want here within reason. We're our own boss. We pick our destiny. We pick and choose what we want to do for that day, and that's how we live life."

In addition, they also receive in-home services. "We have physical therapy, occupational therapy that comes and visits. The OT has done wonders in helping Donna moving her left hand and her left leg which is now paralyzed. PT has been working with me to help strengthen my legs. We have the home nurse to check on us. She came yesterday to wrap my leg," Steven said. For anyone living in a long-term care facility, he has some words of encouragement. "Don't be apprehensive. This is for you. You'll get all the care you need. Plus you'll have the freedom to do what you want as you want. If you like to cook or if you just want to have a bowl of cereal anytime you want you can do it. You want to be your own boss, you can do it." 10



I lived in a developmental center for a long time until I moved into my own home. I have my own key to my house and my own bedroom. My staff understand me.

- Sharon

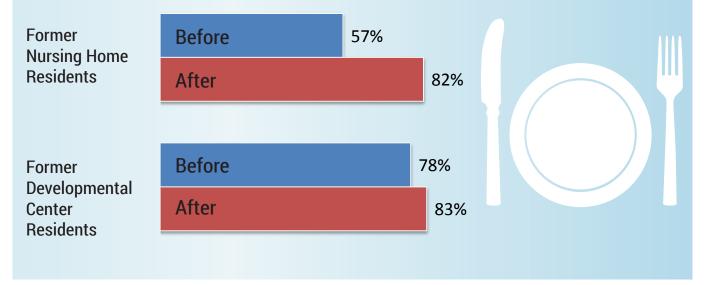


I have the whole apartment to myself. Family and friends can visit me in my home. I am so happy to be independent!

- Betsy

I can eat when I want to

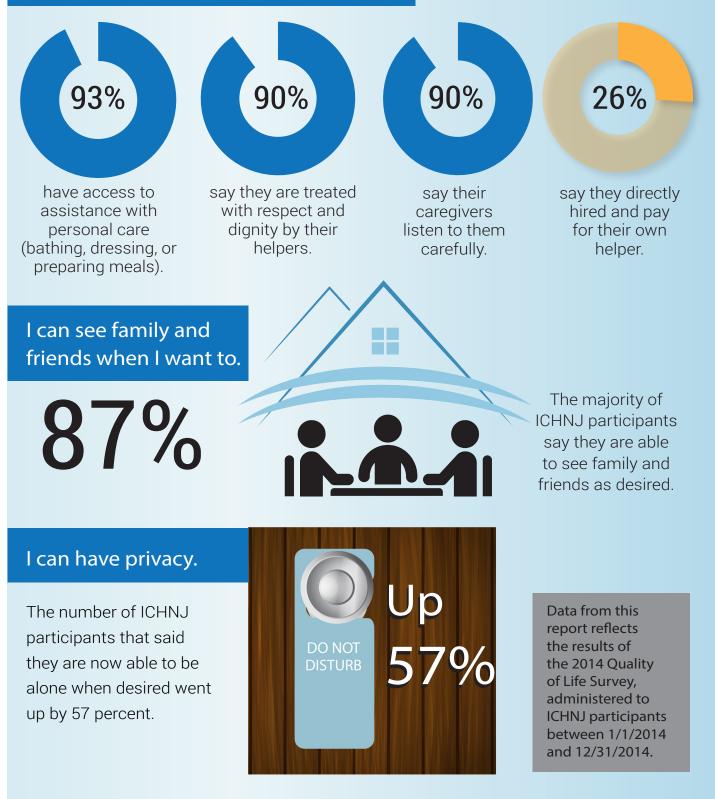
After ICHNJ participants moved out of a facility and back into the community, many more said they had the freedom to eat when they desired.



The graph above reflects the results of the 2014 Quality of Life Survey, administered to ICHNJ participants between 1/1/2014 and 12/31/2014.

Percent of ICNJ Participants Who Said...

I can get the help and care that I need.



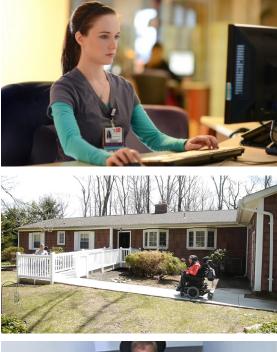


ICHNJ Funded Projects

How ICHNJ is creating more home- and community-based services for everyone

New Jersey has saved more than \$20 million in Medicaid expenditures as a result of helping 1,600+ people to move out of nursing homes and developmental centers. These savings are being invested in projects that will create more possibilities for elderly and disabled individuals to live in the community, including:

- Funding an online career training program for people who work directly with people with disabilities, to promote a more stable and skilled caregiver workforce;
- Contributing funds for the construction of 12 four-person group homes to house people leaving developmental centers;
- Creating a loan program through NJ's Housing and Mortgage Finance Agency (HMFA) to incentivize housing developers to create more housing for people leaving nursing homes; and
- Providing laptops and free employment training to people who have been in nursing homes (and out of the workforce) for a many years and who want to get back to work.





Stakeholder Engagement

The I Choose Home Partnership Group is a gathering of consumers, family members, service providers, and other individuals who have a vested interest in creating more home-and community-based services for people leaving institutions.

The purpose of the Group is to advise policy makers on how to develop a system of community-based care and supports that is consumer-focused and promotes self-direction and choice for people who have been or are currently living in facilities (nursing homes/ developmental centers) and are transitioning to living in a community-based environment. It also serves to evaluate the effectiveness of both ICHNJ and the state's overall effort to move from an institutional to a more community-based system of care and support.

The Partnership Group consists of the following members:

I Choose Home participants/consumers, individuals with disabilities, family caregivers, Centers for Independent Living, ADRC/NWD Representatives, housing representatives, HCBS providers, personal care providers, MCO/ case management representatives, community development specialists, public interest attorneys, peer mentors, and New Jersey State staff. The Stakeholder Group meets several times a year. From these meetings, concrete action and meaningful collaboration has resulted.

For instance, during a conversation about the dire need for affordable housing, one of our housing developer partners offered to dedicate four units in his new affordable housing complex specifically for ICHNJ participants.

In addition, in February 2015 the Partnership Group offered comments to New Jersey's plan to implement the federal Home- and Community-Based Settings Rule. This Rule would redefine the Medicaid-eligible settings currently considered "home- and community-based." This change could have enormous implications for where elderly people and people with disabilities can receive services.



An Akabe Village apartment earmarked for ICHNJ, with wheelchair-accessible features.

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Public Outreach and Community Education

Spreading the Word that "A Nursing Home May Not Be the Only Option"

Many people think that when they or their loved one becomes elderly or disabled and needs substantial help (with bathing, dressing, getting around, etc.), a nursing home or assisted living facility is the first and only option for the care they need. And once someone goes into a nursing home or developmental center, it may seem like there is no way out, especially if the person has given up their home or apartment. Conversely, families who do not want their loved one in a nursing home and choose to keep him/her at home are often overwhelmed and overworked with the burdens of caregiving.

Many low-income people who need some nursing home -type services may be able to age in place or to leave a nursing home with long-term care Medicaid services. Unfortunately, however, many people do not know that these Medicaid services exist.

Informing the public about resources available to them is one of the most important aspects of the I Choose Home NJ program.

In order to spread that message, our Team is on the road nearly every day – at senior expos and fairs, senior centers, professional conferences, colleges, places of worship, government offices, and more. We have spoken on talk radio programs, run ads on NJ Transit trains and buses, and appeared on television. To date, we have exhibited and/or spoken at more than 100 community events.

Our interactive website, www.ichoosehome.nj.gov,

invites people to contact us so that we can connect them with services for themselves, friends, or family. If a person is not eligible for our program, we still take the time to point them to experts in their area who can explore all possible options for home-based services and supports.





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Reaching Out to Nursing Home Residents and Staff

One of the most important functions of the I Choose Home NJ Program is identifying possible participants. To that end, Outreach Coordinators visit all 360 NJ nursing homes at least once per year to speak with residents and educate facility staff about the right of all residents to explore community-based options if they so choose.

Once ICHNJ staff identify an interested resident, they advocate strongly for that institutionalized resident. Even if well intentioned, other players may have a financial or emotional stake in the resident's choice and the resident's voice is not heard and their choices not honored. Social workers play an important role in this situation as they already have certain legal and professional obligations to help residents leave a nursing home if that is their wish. We have sent letters to nursing home facility social workers and administrators to remind them of those obligations and we continually offer our staff as a resource.



A Nursing Home May Not Be the Only Option.



If someone you know: Is living in a nursing home or developmental center; Has or will be there for 90 days or more; Is eligible for Medicaid; and Wants to move back into the community,

I Choose Home NJ may be able to help you move back into the community with low- or no-cost in-home services.



I Choose Home NJ is a partnership among:







