NJ State Transition Plan: 
What Is It & Why Does It Matter?

Prepared and presented by Desiree Kameka
National Coordinator, Coalition for Community Choice
Director of Community Education & Advocacy, MHAF
Dkameka@MadisonHouseAutism.org
Scope of Today’s Lecture

- Why does it matter?
- History of the Final Rule
- What’s in the Final Rule
- Guidance from CMS
- Implementation Timeline
- State Transition Plans Highlights and Trends
- Heightened Scrutiny and North Dakota
- NJ STP Draft & Revision
- Next Steps
“The more you take responsibility for your past and present, the more you are able to create the future you seek.”

--Celestine Chua
"It was like a jail scene, a prison ... Even the soap stunk."

He said he'll never forget the day he got out, in November 1976.

"I was so happy, I jumped for joy. I said, ‘Thank God I'm coming out!’"

Belief most COULD NOT learn or communicate

NO CONTROL, CHOICES, OPPORTUNITY

FORCED SEGREGATION

Viewed to be WITHOUT VALUE or CONTRIBUTION to society

Labeled as DANGEROUS to society
Present Protections

• 1990: Americans with Disabilities Act
• The Supreme Court *Olmstead* Decision: “recognition and unjustified institutional isolation of person with disabilities is a form of discrimination…” -Olmstead, 119 S.Ct. 2176, 2179, 2187

• 2000: Developmental Disabilities Assistance and Bill of Rights Act: “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life …”

• 2014: HCBS Final Rule based on outcome-oriented criteria and an emphasis on person-centered planning

Goal?

More Choices, More Control, More Person-Centered
1.) HUGE demand without nearly enough supply

2.) Little is being done to increase the supply

3.) Institutional attitudes and abuse still occur in ‘community’ settings

4.) Lack of quantity, quality, and accountability in direct care workforce

5.) Homes geographically located in communities does not guarantee one’s experience of relational community. Lack of:

   - Social support / opportunity for relationships
   - Transportation
   - Not enough employment / opportunities
Where do indv. With I/DD live in NJ?

**ESTIMATED NUMBER OF INDIVIDUALS WITH I/DD BY LIVING ARRANGEMENT: FY 2013**

- **With Family Caregiver**: 103,375 (74%)
- **Supervised Residential Setting**: 14,139 (10%)
- **Alone or with Roommate**: 22,846 (16%)

**TOTAL: 14,360 PERSONS**


**Source: 2013 Report**
Over 26,000 individuals with I/DD are living with caregivers over the age of 60 in NJ.
Even with a paid job in the community, market rate rent is unaffordable in New Jersey. Affordable housing vouchers are limited and can not meet the demand.

Source: Priced Out 2012 Report
“The bottom line is that abuse is prevalent and pervasive, it happens in many ways, and it happens repeatedly to victims with all types of disabilities.”

Source: Report on the 2012 National Survey on Abuse of People with Disabilities
www.disability-abuse.com
### Quality, Quantity, Accountability of Workforce?

#### Reasons for not reporting:

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>58% believed nothing would happen</td>
<td></td>
</tr>
<tr>
<td>38% had been threatened or were afraid</td>
<td></td>
</tr>
<tr>
<td>33% did not know how or where to report</td>
<td></td>
</tr>
</tbody>
</table>

“Direct-care occupations are projected to be the 2nd largest occupational group in the US by 2018 reaching 4,322,000 and exceeding the number of teachers, nurses, and law enforcement professionals.”

- Paraprofessional Health-Care Institute 2011
My adult child will:

- Regularly participate in recreational activities
- Have a spouse or life-partner
- Be valued by his/her community
- Have friends in the community with whom he/she shares an interest:
One’s Experience of Relational Community?

INDIVIDUALS WITH I/DD WHO REPORTED ‘SOMETIMES’ OR ‘OFTEN’ FEELING LONELY BY SETTING (2012-2013)

- IDD Specific Institutional Setting: 37%
- Group Home: 41%
- Independent Home/Apt: 43%
- Foster Home: 51%
- Family Home: 40%

“Loneliness and the feeling of being unwanted is the most terrible poverty.”
– Mother Teresa
What is the History of the Final Rule?

In response to Affordable Care Act, federal HCBS regulations needed to be revised:

2008: NPRM for 1915(i) - not finalized
2009: ANPRM for 1915(c)
2011: NPRM for 1915(c)
2011: NPRM for 1915(k)
2012: NPRM for 1915(i) and 1915(k)
2013: NPRM for 1915(c), (i), and (k)
2014: CMS-2249-F/CMS-2296-F published

“The Rule, as part of the Affordable Care Act, supports the Dept. of HHS Community Living Initiative. The initiative launched in 2009 to develop and implement innovative strategies to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living.”

–CMS website
What’s in the Final Rule?

- New regulations and criteria for residential and non-residential settings that use HCBS funding
- Settings eligibility based on outcomes and experiences rather than physical criteria
- Emphasis on integration in, and full access to, community same as those who are not receiving waiver services
- Person-Centered Planning
- Timeline for Compliance
“In this Final Rule, CMS is moving away from defining home and community settings by “what they are not” and toward defining them by the nature and quality of individuals experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based soley on a setting’s location, geography, or physical characteristics.”

-CMS HCBS Fact Sheet
• The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.

• The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

Facilitates individual choice regarding services and supports, and who provides them.
Provider Owned or Controlled Settings

- The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.
Provider Owned or Controlled Settings

- Each individual has privacy in their sleeping or living unit:
  - Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.
  - Individuals sharing units have a choice of roommates in that setting.
  - Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.
- Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
- Individuals are able to have visitors of their choosing at any time.
- The setting is physically accessible to the individual.
Any modification must be supported by a specific assessed need and justified in the person-centered service plan:

- Identify a specific and individualized assessed need.
- Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
  - Document less intrusive methods of meeting the need that have been tried but did not work.
- Include a clear description of the condition that is directly proportionate to the specific assessed need.
  - Include regular collection and review of data to measure the ongoing effectiveness of the modification.
- Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
  - Include the informed consent of the individual.
- Include an assurance that interventions and supports will cause no harm to the individual.

Exceptions to the Requirements
Settings NOT Eligible for HCBS Funding

Settings that are not home and community-based are defined at §441.301(c)(5) as follows:

• A nursing facility;
• An institution for mental diseases;
• An intermediate care facility for individuals with intellectual disabilities;
• A hospital; or
• Any other locations that have qualities of an institutional setting, as determined by the Secretary.
Settings PRESUMED NOT Eligible

The following settings are presumed to have the qualities of an institution:

• any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,

• any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or

• any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.
First test case: Life Skills & Training Center, Grafton, ND

- CMS contractor NORC conducted review
- Information provided by State and other parties
- Determine that is does not have qualities of an institution and
- Does have the qualities of HCBS

CMS determined LSTC meets HCBS setting criteria based on access to and integration of residents in community.
• No setting size, physical characteristics, or person limits
• Did not expressly rule out disability-specific settings
• Focused on outcomes and experiences
• Emphasized authority and mandates Person Centered Plans be created and reviewed in order to access funds
• Five-year implementation period
• Apply to non-residential as well
• Set a baseline, but gave states the flexibility to implement more restrictive regulations
CMS Guidance

- CMS Guidance expanded on the Final Rule and identified settings that are presumed to be institutional.

- Settings that have these two characteristics alone might, but will not necessarily, meet the criteria for having the effect of isolating individuals:
  
  #1 – The setting is designed specifically for people with disabilities, and often even for people with a certain type of disability.
  
  #2 – The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them.
Settings that isolate people receiving HCBS from the broader community may have *any* of the following characteristics:

- The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities:
- People in the setting have limited, if any, interaction with the broader community
- Settings that use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion)
Non-exhaustive list of examples of residential settings that typically have the effect of isolating people receiving HCBS from the broader community:

- Farmstead or disability-specific farm community
- Gated/secured “community” for people with disabilities
- Residential schools
- Multiple settings co-located and operationally related (i.e. operated and controlled by the same provider)
  - Excluded CCRCs (Continuing Care Retirement Communities)
Jan. 10, 2014 - Final Rule published

March 17, 2014 - Transition Clock Starts

March 17, 2015 - State Transition Plans Due

March 17, 2019 - Transition Complete, All Settings Must be in Compliance
CCC STP Concerns

CCC letter to CMS cited concerns:
• States were reverting back to physical characteristics instead of outcome oriented criteria
• States were telling advocates and providers that campus settings, farmsteads, and intentional communities would not be funded by CMS
• States were creating restrictive criteria that would automatically exclude settings from being evaluated or put through the higher scrutiny process
Providers, let alone individuals with I/DD and/or their parents, were not educated by most states about the requirements of Final Rule, therefore continued education for advocacy is needed.

Some STP's were dense (40 - 500 pages). Plain language was not used to inform those with disabilities of these changes that will influence their life.

Most are using provider self-assessment and not surveying consumer- not good if assessment tool is not outcome oriented.

PCP will be integral for the right to choice, yet was not required to be part of the STP.
State advocacy efforts (besides writing letters and showing up at public comment):

• Ohio - focused on in-person meetings in getting legislature support. 16 of 18 members of Congress signed joint letter to HHS Sec. Burwell with concerns regarding their State Medicaid Agencies exclusion of farmsteads in STP draft.

• NJ/MA/OH - Created petitions, facebook page, and blog to help educate stakeholders and share concerns.

• FL - STP included assessment tool with added physical characteristics criteria
State advocacy efforts (continued):

- NV - Submitted draft language to include definition of “community,” which was included in STP; also pushed for stakeholder input resulting in 5K surveys, 800 inputs
- MA - Workgroup created of providers who were listed in STP as not currently being compliant to help reach compliance, 5 bed rule to licensed HCBS settings
- Multiple - Requested the development of a transition advisory team comprised of stakeholders
Additional regulations proposed by NJ DHS:

- 75% Mandated Integration
- 4/6 Bed Limitation
- Restriction of 25% of Total Units for HCBS Recipients
- Exclusion of Farmsteads
75% Mandated Integration

“The revised STP requires that individuals in day programs spend the majority of their time engaging in integrated activities with the broader community of non-HCBS recipients inside and/or outside of the day facility. DHS will work with the contracted provider agencies to develop policies and protocols in this regard. Further, the STP was revised to reflect that certification of day programs will include the review of plans from day providers to demonstrate how meaningful community engagement will be provided.” (p. 17-18)
“The STP was revised to clarify that the development of any new congregate housing settings will need to comply with the guidelines on group home size contained in the federal Money Follows the Person Demonstration Program. However, NJ will allow group homes with a service level up to 50% higher than the standard in the federal MFP program in homes where medical care is provided, with prior approval from DHS. These guidelines align with DDD’s current practice and the HCBS Final Rule. The STP also clarifies that the provision applies to new settings only and will not be applied retroactively to existing settings.”

(p. 14)
Restriction of 25% of total units for HCBS recipients

“The revised STP clarifies that the provisions will apply to new settings, only, and not be applied retroactively to existing settings.” (p. 14-15)
Restriction of 25% of total units for HCBS recipients

“DDD has adopted a policy requiring all new integrated (non-congregate) settings align with the definition of integrated housing contained in the current federal U.S. Department of Housing and Urban Development (HUD) 811 Project-Based Rental Assistance (PRA) Demonstration program. These guidelines align with the HCBS Final Rule. These policies will cover both licensed settings and unlicensed, independent residential settings where individuals receive HCBS services through the CCW or the Supports Program. (Please note that private residential homes where individuals own their own homes, or where they live with a family member, are not governed by these policies.” (p. 15)
Exclusion of Farmsteads

“The revised STP states that when considering any new development, DHS will consider proposals for settings that comport with the HCBS final rule and with any other applicable state and federal regulations.” (p. 32)
## Next Steps

Read the NJ State Transition Plan!

### DHS/DDD Statewide Transition Plan – Status Report

The summary below is our preliminary analysis of the final plan issued on April 17, 2015. Please check back for updated content. This document follows the framework of the DHS document, “STP Issues of Note.” Blue text denotes DHS language.

<table>
<thead>
<tr>
<th>Draft Plan Issue</th>
<th>Autism New Jersey Recommendation</th>
<th>Revised Plan Language</th>
<th>Policy Objective</th>
</tr>
</thead>
</table>
| 1) Increase community-based living arrangements  
- The draft plan stated DHS' commitment to increasing community-based options through capital financing and funding for related costs. | Fully supported. | N/A  
(p.16) | N/A |
| 2) Day Activities  
- The draft plan stated that recipients of HCBS must spend 75% of their day activities in the community in settings with people who are not recipients of HCBS. | Given the draft STP's 75% mandate, the community was understandably concerned that this rule was not in the best interest of some individuals. Thus, Autism New Jersey recommended the removal of the percentage in favor of a policy that would offer more flexible ways to meet community integration goals in a manner consistent with individuals' person-centered plans. | "The revised STP requires that individuals in day programs spend the majority of their time engaging in integrated activities with the broader community of non-HCBS recipients inside and/or outside of the day facility. DHS will work with the contracted provider agencies to develop policies and protocols in this regard. Further, the STP was revised to reflect that certification of day programs will include the review of plans from day providers to demonstrate how meaningful community engagement will be achieved." | Achieved |
Did your state adequately reflect public comment in revisions?

If so, thank DHS.

If not, contact CMS and tell them how your state neglected to solicit enough stakeholder feedback and/or revise based on sufficient public comment.
DHS will seek input for assessment tool for setting assessments.
• Read and give feedback.
• Remove questions that are based on physical characteristics.
• Add questions that will identify and document barriers to access

Example:
How many times a month does Maria go out to dinner?
How many times does she want to go out to dinner?
What prevents her from going out to dinner as often as she would like?
See if your state has created a transition advisory committee / workgroup and ask to join!

Stakeholders should include:
- HCBS recipients who reside in different settings
- Parents of HCBS recipients
- Service Providers
- Direct Support Professionals
- Affordable Housing Developers

If none exist, request to create one.
Next Steps

Build relationships with your legislatures!

They MUST become more aware of the statistics and stories of their constituents with I/DD who are struggling to be supported in their community and find appropriate affordable housing options.
Next Steps

Start the Person Centered Planning Process!

- Look at the Final Rule Requirements for PCP’s: [www.HCBSAdvocacy.org](http://www.HCBSAdvocacy.org)
- Increase self-advocacy skills of HCBS recipients so they can lead the process as much as possible
Next Steps

Co-creating an Array of Opportunities Full of Choices

- Choice of home/room to rent or own, as an individual or family
- Choices for service providers, smart home and assistive technology
- Choice for more or less structure in routines and environment
- Choice of roommates (with or without I/DD)
- Choices in amenities the community may offer
- Choices in planned and unplanned activities
- Choices in where and what to eat
- Choices to be in leadership roles or just enjoy being a resident in the community
- Employment options
Sweetwater Spectrum (Sonoma, CA)
Faison Residence (Richmond, VA)
Erik’s Retreat (Minneapolis, MN)
NeuroDiverse Cohousing (FL, NC, WA)
North Street Neighborhood (Durham, NC)
The Arc Village (Jacksonville, FL)

The Arc Village will utilize the following to minimize costs to residents:
• Natural supports
• Community partnerships
• Faith-based organizations
• Volunteers
• Civic groups
• College mentors
• AmeriCorps

Living accommodations
• 68 one-bedroom, one-bath apartments
• 29 two-bedroom, two-bath

Features:
• Living and dining spaces
• Full kitchens and laundry
• Bedrooms and bathrooms designed for maximum accessibility
• Wide porch that invites gatherings
• Wide sidewalks to encourage walking
Nationwide, less than 250,000 more people with I/DD were funded to be supported outside their family home. Over 850,000 individuals are currently living with caregivers over the age of 60... Where will they find their home?

None of us can do this alone… Working together, solutions are possible!
For More Information:

www.MadisonHouseAutism.org
www.CoalitionForCommunityChoice.org

Desiree Kameka
dkameka@madisonhouseautism.org

*Presentation Copyrighted. For private use, not to be duplicated or circulated without permission. Info@MadisonHouseAutism.org