Wanting to Go Home… Waiting to be Asked: Section Q and People with Developmental Disabilities

A Training on Implementation of MDS Section Q Referral Questions

What We'll Learn About

- What is PASRR?
- What is the MDS? Why do we need an MDS?
- What did CIDNY learn about Section Q?
  - Interviews with stakeholders
  - Case studies
- What do we recommend?

By the end of the training, participants will be able to:

1. Understand the relationship and differences between PASRR and the MDS Section Q;
2. Describe the federal Section Q referral requirements and understand the philosophy that supports them;
3. Understand how OPWDD's Transformation Agreement relates to Section Q;
4. Articulate the rights of people with developmental disabilities under these new rules;
5. Articulate the perspectives of stakeholders;
6. Express the ways other states have complied with Section Q;
7. Develop and share ideas for improving the Section Q referral process.

PASRR Preadmission Screening and Resident Review

PASRR

- To prevent inappropriate admission into nursing facilities unless determined to require nursing facility level of services;
- To “prevent deterioration in condition, enhance quality of life, and possibly to help prepare the person to return home or to another community-based residential opportunity.”

PASRR (cont'd)

- PASRR Coordinator completes Level II screen—together with service coordinator, vacancy management liaison and "others."
- Periodic conversation between the nursing facility and PASRR Coordinator to determine:
  - whether person can return to prior OPWDD residential placement;
  - whether alternate placement is indicated;
  - whether person's condition necessitates long-term stay in nursing facility.

PASRR (cont'd)

- If the screen is being conducted on someone already in a nursing home, a conversation occurs between the PASRR Coordinator and the nursing facility:
  - To determine whether someone who has been living in an OPWDD-certified residence is appropriately placed in a nursing facility;
  - To share information to "enable the Nursing Facility to provide more person-centered care to the individual."

The Minimum Data Set
MDS

MDS

The MDS is a federally mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes.

The MDS question, Section Q is:

- asked of all nursing home residents;
- asked according to a prescribed schedule.

All means all—no exemption for people with developmental or cognitive disabilities.

MDS Section Q: Discharge Planning

Section Q referral questions are a tool to assess a person's desire for deinstitutionalization.

What is difference between Section Q and the PASRR process?

- Section Q is a conversation with the people with developmental disabilities to see if they want to talk to someone about returning to the community.
- PASRR is a placement conversation between OPWDD and the nursing facility about the feasibility of particular placements and services that can be put in place.

What is the philosophy that underlies Section Q?

The U.S. Supreme Court held in Olmstead v. L.C. that unjustified segregation of people with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act.

- "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life.“
- "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

CMS Rationale

CMS.gov
Centers for Medicare & Medicaid Services

CID-NY

- Section Q, Item Q0500B requires that residents be asked the question directly and formalizes the opportunity for them to be informed of and consider their options to return to community living.
- This ensures that the resident's desire to learn about the possibility of returning to the community will be ascertained and appropriate follow up measures will be taken.
- The goal is to obtain the informed choice and preferences expressed by the resident and to provide information about available community supports and services.

What is the State's philosophy that underlies Section Q?

"People with disabilities have the right to receive services and supports in settings that do not segregate them from the community; it is a matter of civil rights."

- Governor Andrew M. Cuomo

Federal and state philosophies come together for people with developmental disabilities

Moving out of institutional settings and into the community is a critical component of OPWDD's Transformation Agreement with CMS.

- In 2014, there were 1,057 people with developmental disabilities in nursing homes.
- OPWDD Agreement with CMS for 2013-2016 requires transition of 875 people to less restrictive settings, including 100 residents of nursing facilities.

MDS' Section Q is now truly "person-centered"

"The underlying intention behind the revisions to Section Q of MDS 3.0 is to insure that all individuals have the *opportunity to learn about home and community-based services and have an opportunity to receive long term care in the least restrictive setting possible. "*

MDS' Section Q is now truly "person-centered" (cont'd)

- Deliberate shift in focus from nursing facility staff making the determination.
- Not about feasibility of discharge and the nursing facility is **not to assume** that any particular resident is unable to be discharged.

MDS' Section Q is now truly "person-centered" (cont'd)

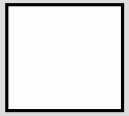
- Residents are asked whether they want to speak to someone about getting care in the community.
- If they say, yes, they are to be referred to an outside agency.

http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment Instruments/NursingHomeQualityInits/NHQIMDS30-ArchivedRAIManuals.html see, MDS 3.0 RAI Manual V1.08 [ZIP, 31MB] , go to Section Q.

What is the Section Q process for people with developmental disabilities?

- Once a resident with a developmental disability says they want to learn more about moving back to the community, they must be contacted by the outside source within 10 days.

MDS 3.0 SECTION Q: Question 500

Q0500. Return to Community	
Enter Code 	**B. Ask the resident** (or family or significant other or guardian or legally authorized representative if resident is unable to understand or respond): **"Do you want to talk to someone about the possibility of leaving this facility and returning to live and receive services in the community?"** **0. No** **1. Yes** **9. Unknown or uncertain**

MDS 3.0 SECTION Q: Question 490

Allows a resident to opt out of being asked the question every few months.

Q0490. Resident's Preference toAvoid Being Asked Question Q0500B Complete only if A0310A = 02, 06, 099	
Enter Code	**Does the resident's clinical record document a request that this question be asked only comprehensive assessemnts?** **0. No** **1. Yes** ⟶ Skip to Q0600, Referral **8. Information not available**

MDS 3.0 SECTION Q: Question 550

Permits resident to opt out of being asked every few months.

Q0550. Resident's Preference to Avoid Being Asked Question Q0500B Again	
Enter Code ☐	A. **Does the resident** (or family or significant other or guardian or legally authorized representative if resident is unable to understand or respond) **want to be asked about returning to the community on <u>all</u> assessments** (Rather than only on comprehensive assessments.) **0. No** – then document in resident's clinical record and ask again only on the next comprehensive assessment **1. Yes** **8. Information not available**
Enter Code ☐	B. **Indicate information source for Q0550A** **1. Resident** **2.** If not resident, then **family or significant other** **3.** If not resident, family or significant other, then **guardian or legally authorized representative** **8. No information source available**

MDS 3.0 SECTION Q: Question 600

Has a referral been made?

Q0600. Referral	
Enter Code	**Has a referral been made to the Local Contact Agency?** (Document reasons in resident's clinical record) **0. No** – referral not needed **1. Yes** – referral is or may be needed (For more information see Appendix C, Care Area Assessment Resources #20) **2. Yes** – referral made

When people with developmental disabilities say yes

- OPWDD, nursing homes and DOH provide the New York Association on Independent Living (NYAIL) with a list of individuals who have responded positively to Section Q and PASRR.
- DOH sends NYAIL the list of people who have responded positively to Section Q approximately 3-4 months after MDS is administered.
- NYAIL plans for a visit at the nursing facility and informs the regional OPWDD office and PASRR coordinators and nursing home liaisons of plans for a visit.

When people with developmental disabilities say yes (cont'd)

- NYAIL comes into the nursing home to speak to the resident to provide information on various options.
- NYAIL staff gets consent forms from those interested in transitioning to the community.

When people with developmental disabilities say yes (cont'd)

- NYAIL informs OPWDD/PASRR Coordinators, Nursing Home Liaisons and Local Contact Agency (local open doors ILC)that the individual chooses to participate.
- Local Contact Agency confirms eligibility, contacts nursing facility discharge planner, participates in discharge planning.

When people with developmental disabilities say yes (cont'd)

- NYAIL develops a person-centered transition plan for the individual and works with the discharge planning team to make sure that the plan is complete.
- NYAIL participates in the person-centered planning meetings.

When people with developmental disabilities say yes (cont'd)

- NYAIL offers peer assistance to transitioning individuals.
- NYAIL ensures community preparedness education is provided.

CIDNY's Project

How is Section Q working for people with developmental disabilities?

CIDNY Project Objectives

- Evaluate the current New York State process for complying with Section Q;
- Make recommendations for application to people with developmental disabilities; and
- Develop training for local organizations on how people with developmental disabilities can improve their chances of receiving care in the most integrated setting.

Project Objectives

- Interviews with people with developmental disabilities who have transitioned to the community following nursing facility stays;
- Interviews with advocates for people with developmental disabilities;
- Interviews with stakeholders (DOH, OPWDD); Local Contact Agencies; nursing home ombudsmen; nursing facility staff.

Project Process (cont'd)

- On-line surveys and interviews of New York City nursing home staff who conduct Section Q;
- Interviews with representatives of local contact agencies; ombudsmen, consumers and their advocates;
- Identification and interviews with four (4) states with "best practices."
- Report on findings;
- Make training available regarding Section Q.

CIDNY Section Q Interviews

People with Developmental Disabilities
Who Transitioned to the Community

“…Ask in a nice way…”

Ms. D has developmental and other disabilities.

- The nursing home staff assumed that because Ms. D was developmentally disabled, she could not understand them. They didn’t talk to her.
- Ms. D. stopped talking and became seriously depressed.

“…Ask in a nice way…” (cont’d)

“People should be helped because they want to Come home and need help to get out. Social workers (in the nursing home) should ask in a nice way – not nasty. They should talk nicely.”

“Everyone should be asked if they want to go home. I saw people there who wanted to go home.”

“They don’t ask you what you want to do...”

- Mr. R was in a nursing home for five years. He has mild developmental disabilities, depression and anxiety. Mr. R does not think he was ever asked if he wanted to leave.
- Mr. R says that if someone answers “yes” to the Section Q question, they should get help to plan leaving the home.
  - *“They don’t ask you what you want to do. Patients need more information. The question should be, where do you want to live or do you want to leave the home.”*

“I should be asked; it is my right to be asked. Sometimes the family is not right…”

Individuals with developmental disabilities feel that family views do not trump the individual’s wishes:

Mr. A, has moderate developmental disability and schizophrenia. He was in the nursing home following leg surgery. He says he was never asked if he wanted to leave – he says: *“I should be asked; it is my right to be asked.”*

What if there is family opposition?
“Sometimes the family is not right. It is the person’s right, an individual right to decide what they want.”

CIDNY Section Q Interviews

Advocates

Advocates recommend an expanded discussion and family education

- Advocates first say that Section Q can't be asked alone. People with developmental disabilities may need an exploration—how would meals be different? How about getting dressed and other activities of daily living?
- Advocates feel that families are not educated about services that are available for their family member with a developmental disability. Some tried to do (transition) on their own, but couldn't put the services together and now don't believe services exist in the community.

Advocates say education is needed to overcome assumptions about people's abilities

- Advocates for people with developmental disabilities said that context is a big issue, people tend to see people with developmental disabilities in a nursing home and think that's all they can be – "they're in the nursing home for a reason, why else would they be here?"
- If a person is in the apartment, he's seen as capable. The same person with a different service coordinator could be put in a group home.

Advocates say education is needed to overcome assumptions about people's abilities (cont'd)

"I would say, don't assume the context reflects the person's abilities. People with developmental disabilities are a broad range of people – it's variable, you can't make a rule about what works and what doesn't.

"Sometimes people believe that if someone can't talk, they can't live on their own; or because they are physically able they can live alone..."

Advocates say education is needed to overcome assumptions about people's abilities (cont'd)

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"Nursing home staff need training on how to ask people the question and on choice and person-centered approaches."

"Staff will say things like, 'This person has medical needs and can't live in the community.' They need to have some kind of training about that. Materials need to be better."

"A lot of times these things are clinically done, and it's a checklist rather than helping people in the exploration process."

CIDNY Section Q Interviews

Nursing Home Discharge Planning Staff

Some nursing facility staff are not asking the Section Q referral question or not referring

56.1% of nursing home staff do not believe Section Q is helpful and many are not asking the question, often because they believe discharge is not feasible.

"If there is no viability – I don't refer it. I only refer if there is a chance they could get services in the community."

Facility staff are not asking
(cont'd)

"Most of us don't always interview the resident – no time, we put down answers we had before – most of the time."

"I have a resident with mild impairment, but he does not have a back-up plan and the family is not interested in him going to the community. Why should we ask the question?"

"I don't see the need to ask this question. I feel that we can determine through our meetings with residents and/or families what discharge planning should be, if at all."

Facility staff believe that people with cognitive or intellectual disabilities won't understand Section Q

- 74.2% believe that the question will not be understood by people with intellectual or cognitive disabilities.
- Only 54.9% of discharge planners say they have asked the question of residents with a diagnosis of developmental or intellectual disability.

Facility staff believe that people with cognitive or intellectual disabilities won't understand Section Q (cont'd)

"Some residents with cognitive or intellectual disabilities don't understand the question."

"Residents with developmental disabilities are unable to understand the kind of care necessary to keep them safe in the community."

Facility staff believe that people who are asked will be difficult

Nursing home discharge planners overwhelmingly (72.7%) believe that residents are difficult to deal with when they have different goals from family members/guardians.

- *"Speaking with this population requires simplicity in explanation for processing and has led to increased anxiety regarding what will happen to them."*
- *"Once asked, people for whom discharge is unrealistic perseverate on the possibility, creating disappointment when it doesn't work out."*

Nursing facility staff believe that family members will be upset

Many of those who think the Section Q referral question is not valuable state that family members will be upset or burdened by discharge. Respondents seem to believe that family concerns trump the resident's desires and goals.

- *"I have a resident that wants to go home but his daughter cannot and will not take him home. She is very upset that we ask this question."*
- *"We need to take into consideration that a lot of the burden is placed on family members to provide care outside of home care and this may be an unrealistic option…"*
- *"Have to bring in the designated representative who has to be involved; we have to know what is realistic and are we all in agreement. We have to determine whether the resident can make the decision for themselves."*

Facility staff believe that community resource limitations pose barriers to discharge

While the majority believe that working towards discharge for people with developmental disabilities has worked well, 40% have had problems that they relate to unfamiliarity with community resources:

- belief that resources are inadequate to meet resident needs, or
- not knowing who to contact for information.

Facility staff believe that community resource limitations pose barriers to discharge (cont'd)

"The resources for housing are so limited, it takes months to even get someone from NYS to contact you about the application needed for the housing."

"I have residents with level II for MR/DD and they are waiting years for placement. There does not seem to be enough availability for d/c (discharge) to community."

"This question is being asked to residents who are cognitively impaired or intellectually disabled however; there are very few resources available to assist these residents. It's almost providing sense of false hope."

CIDNY Section Q Surveys and Interviews

Local Contact Agencies

Community resource limitations pose barriers to discharge

LCA interviews focused on Section Q implementation validated some of the nursing home staff concerns about barriers to deinstitutionalization and related to reluctance to ask Section Q.

- One of the most difficult barriers to community transition that both nursing home staff and the LCA identified is the lack of affordable, accessible housing in the City.

LCAs: Some nursing facility discharge planning staff are not asking Section Q

In many cases, LCA staff said that they felt most Facilities are not even asking the question. Most of those interviewed said that many facilities had never referred a resident.

- “We only get referrals from about 25% of the nursing homes in our catchment area.”

LCAs: Some nursing facility discharge planning staff are not asking Section Q (cont'd)

- One interviewee said that some social workers feel it is a conflict of interest to ask the question since they work for the nursing home and need to keep beds filled. The high turnover of social workers was also seen as a problem.
- *"We often do not see the same social worker twice. The new social worker would not know anything about the referral."*

LCAs: Monitoring is key to success

- Across the State, every LCA brought up the lack of State monitoring as a barrier to the Section Q referral question.
- LCAs noted that DOH does not enforce the mandate to ask the question.

LCAs: Monitoring is key to success
(cont'd)

- One interviewee said that when she discussed with a social worker that referrals were supposed to be made for residents who say, "Yes," she was told: "We just had our survey and Section Q was not even mentioned. I don't think DOH knows about it."
- Most LCA staff felt there is no accountability – "No enforcement – no one making sure it happens."
- "Is the State holding nursing home social workers accountable? It seems as if Section Q referrals are nobody's priority."

What can be done to improve the system?

Monitoring

- LCAs felt that nursing homes must be held accountable. The State should follow up with those facilities that are not referring anyone; such nursing homes must be given citations.

What can be done to improve the system? (cont'd)

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Education

- LCAs feel that nursing homes, residents and families must be educated about the reason the question is asked and what happens once the question is answered, yes. Among their ideas:
  - Materials for residents and family members telling them their rights to be asked and what the process entails should be mandated to be given out in the nursing home – in the admissions packet and often thereafter;
  - Just as there is a poster letting residents know about the ombudsman, there should be a poster posted in a place where residents and families congregate letting them know about the LCA.

CIDNY Section Q Interviews

Long Term Care Ombudsman Perspective

Nursing facility social workers are not asking the question or making the referral

- The New York City Ombudsman feels that nursing home social workers do not fully understand the mandate to ask the Section Q referral question.
- Residents are not being given a choice. Instead, social workers based on their perception of a safe discharge, are making the decision.

Nursing facility social workers are not asking the question or making the referral (cont'd)

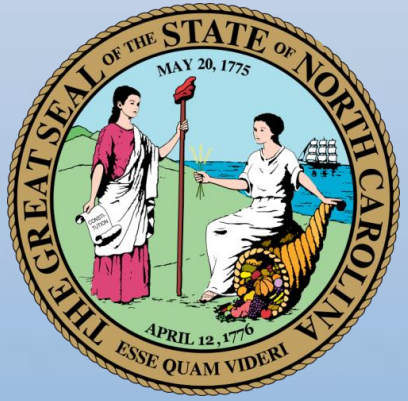
The Ombudsman believes that if the resident says yes, the facility tries to dissuade them.

- "Social workers are not getting the right training. They believe the referral should only be made if there is an appropriate discharge plan—rather than allowing for self-determination."

Nursing facility social workers are not asking the question or making the referral (cont'd)

- The Ombudsman strongly feels that social workers need training on person-centered care, which encourages residents to make their own choices and have more control over their life.
- She believes that there needs to be better communication between all the parties and there should be a statewide policy on ombudsman participation.

CIDNY's Case Studies of Four States



Involve all stakeholders from the beginning

- Each of the four state programs reviewed began by bringing together all of the stakeholders to make sure that all “bought in” to the idea that nursing home residents can be transitioned back to the community.
- Committees formed to develop referral and transition process and training curriculums. Allowed for better coordination among state offices and may have eliminated potential problems. In some cases, committees identified various stakeholder concerns to deal with in the trainings.

Coordinating all state entities

Participation of the ombudsman

- All of the states involved the ombudsman office from the beginning and during the implementation.
- In North Carolina, the State Ombudsman's Office developed a memo for ombudsmen on how to work with the LCAs.

Coordinating all state entities
(cont'd)

- In **Virginia**, in addition to being part of the original group developing the materials and protocols, the local ombudsmen made contact with nursing homes and discussed the changes.
- In **New Hampshire**, the State Long Term Care Ombudsman participated in development of implementation of Section Q and supported the education plan by providing alternative staff coverage of intake while the intake coordinator and Section Q trainer went to various nursing homes and other locales to educate.

Coordinating all state entities
(cont'd)

- In **Minnesota**, the Ombudsman Office was involved in the three-day retreat with other stakeholders and now partners with the Local Contact Agencies (Senior Age Link Line).
- Most states worked hard to make sure there was coordination among state offices and key players.

Coordinating all state entities
(cont'd)

- **Virginia** developed a "Statement of Understanding" between the Virginia Department of Medical Assistance Services, Virginia's Nursing Facilities, Local Contact Agencies and Transition Coordination Providers."
  - outlines the roles of all the stakeholders, has a workflow chart, gives rationale for the changes to Section Q, and lists all roles and responsibilities.

Coordinating all state entities
(cont'd)

- **Virginia** "Authorization to Use and Exchange Information": how to share information on a resident with all needed agencies, including Centers for Independent Living, who can jointly provide or coordinate services for individuals with complex needs.
  - State appointed a State Section Q Coordinator. The Coordinator educates nursing homes, problem solves, takes family calls, etc.

Coordinating all state entities
(cont'd)

New Hampshire started a team of professionals to help individuals transition to the community.

- includes the Choices for Independence staff person,
- the independent case manager,
- nursing home facility staff person arranging the transfer or discharge, and the resident.

If there was a previous history of adult protective services involvement then they are also invited. The ombudsman is also involved if asked by the resident.

Developing readily accessible written materials outlining process and rationale

- All the states developed materials for stakeholders delineating different roles and clearly defined the process.
- Materials were posted on state websites.
- Most materials were focused on the LCAs and the nursing home staff, and on the referral process.

Developing readily accessible written materials outlining process and rationale (cont'd)

- **New Hampshire's** manual gave nursing homes tips conducting discharge planning and how to relate to the ombudsman.
- **North Carolina** developed a "Personal To-Do List for Transition Next Steps" for residents/family members and a brochure for residents/family members on their rights. Other materials included ideas for nursing homes on how to use the brochure with their residents

Developing readily accessible written materials outlining process and rationale (cont'd)

- **New Hampshire** stakeholders (including nursing facility management and staff) were active in developing plans for the referral process and related deliverables. Their participation in training curriculum development led to an ownership in the new Section Q referral process.
- On-going outreach to nursing facilities during the development stages of the referral process promoted greater support and buy-in and ultimately, successful trainings.
- Interactions provided insight into nursing facility training requests and needs.

Developing readily accessible written materials outlining process and rationale (cont'd)

- **New Hampshire** developed a video that can be streamed online. The video is another way to help explain the process; it can be viewed at any pace and remains online.
- **Minnesota** developed material for nursing home residents/family members as well and requires all nursing homes to give Return to Community brochures to all new admissions.

Training all stakeholders

- **Virginia** noted, “Education must be constant. Referrals do go up when training is done.”
- All of the states developed training describing the different roles. Training focused on the process, person-centered care and resident choice.
- A few of the states continue to conduct trainings. Most agreed that constant training is crucial.

Training all stakeholders (cont'd)

- **North Carolina** enlisted Disability Rights, NC to conduct additional training.
- **New Hampshire** has a dedicated person whose main function is to help nursing homes implement Section Q by teaching them about person-centered care.

Mandating significant qualifications for LCA staff

Two of the states require a high level of competence in those who counsel residents.

- In **Minnesota**, counselors must have a minimum of a BA degree from an accredited program of Social Work, Gerontology, Nursing or a related human services field. Must also be able to encourage self-empowerment and recognize the right of people to make their own choices. They must have a Boston University Certificate in Aging.
- In **North Carolina**, LCAs must be "Certified Option Counselors," to make sure that they know how to be "person-centered" and objective, letting the resident make the decisions.

Focusing on person-centered care

- *"I am trying to change the "old school" mentality of nursing homes – that many people cannot be transitioned – I am always trying to change that attitude."* (**Virginia**)
- All states focused on the rationale for the new Section Q: giving the resident a voice and a choice;
- Placing the resident at the center of decision-making; and introducing person-centered care. Training often focused on person-centered care as well as the specific referral process.

Focusing on person-centered care
(cont'd)

- **New Hampshire's** online video discusses how a person-centered approach focuses on individual choice and control.
- It helps nursing home staff deal with problems that might arise by discussing how the question about referral might be asked.
- It urges staff to first have a conversation with the resident about his or her needs and desires – what makes a home for them? This is a way to get to know the resident before asking the question.

Monitoring the system

All of the states monitor some part of the system.

- **New Hampshire** contracted with its University for a data analyst to gather data to see whether the number of "yeses" to the referral question is close to the number of residents who are referred to the LCA. They have been reporting this data monthly to survey staff.
  - State hopes to look at other items in the MDS such as preferences and ADLs (activities of daily living) to see why some residents are not being referred or which residents are being referred.

Monitoring the system (cont'd)

- **North Carolina** is focused on making sure that the management of the nursing home has "bought into" the whole concept of the Section Q question.
- In the past they looked at regions of the State where there were zero referrals and offered training.
- This year, "inreach" requires the LCAs to go into two nursing homes with zero referrals to talk to staff about intent of Section Q question, to help them understand their role and to learn how they can work together.

Monitoring the system (cont'd)

Virginia: all referrals are entered into the State's web portal. Section Q Coordinator receives and tracks reports of all referrals quarterly. If she finds that some nursing homes are not referring residents, she calls them and asks them if they understand the purpose of Section Q and How to conduct the process.

- She deals with them one-on-one and through training.
- Last fall, the Coordinator started to look at the corporations that own facilities in the State. She decided to talk directly to the individual in the corporation who works with the social workers about Section Q and its importance.

Need for survey and certification to take a proactive role

- At least two case study states do not specifically look to make sure the nursing home is complying with the Section Q mandate.
- Although the federal government mandates that all nursing homes must ask the referral question, there is no regulation attached and no specific survey task, so it is difficult to get the survey and certification staff to make this a priority.

Need for more serious consequences for facilities that do not comply

"Until there are negative consequences, the facilities will not aggressively pursue coding – asking the question – they will not pursue aggressive discharge planning with hard to place residents." (**Virginia**)

- Non-compliance brings little sanction to nursing homes. Since there is no regulation attached, the only way a citation can be issued is if the non-compliance is related to other regulations.
- Even if a citation were issued, it is unclear at what severity it would be issued. Unless a citation is cited as "harm," it does not lead to any serious sanctions.

CIDNY's Recommendations

Recommendation One: The Federal Government Should Require That A Neutral Party Ask the Question

- The Federal government should require that a neutral party ask the referral question.
- The Federal government should develop regulations specifically tied to asking the referral question and surveyors must be required to review this on each annual and certification survey.

Recommendation Two: Bring all stakeholders together

- Bringing all stakeholders together helps with buy-in to the process as well as creative solutions to problems that might arise. All then understand national policy for Section Q and strategies for overcoming problems with asking the Section Q question, particularly for people with developmental disabilities.

Recommendation Three: Train nursing home discharge planners to ask the question

Nursing facility discharge planners' training should include:

- the importance of Section Q referral question,
- their role,
- the role of the LCAs,
- the community resources available,
- the rights of residents and person-centered planning,
- the skills and abilities of people with developmental disabilities, and
- working with individuals and family members in a respectful way.

Recommendation Four:
Involve Ombudsmen

- Ombudsmen have an important role to play in making sure that nursing home discharge planners and social workers are asking the question and are asking the question in an appropriate way.
- The state ombudsman should develop ways in which local ombudsmen will be involved.

Recommendation Five: Improve the State Role

New York State should make monitoring nursing facilities a priority to ensure that the Section Q referral question is asked and referrals are made.

- NYS must gather data demonstrating which facilities are not referring residents.
- NYS must be required to meet with nursing homes not referring residents to explain the need to refer and to explain their role.
- NYS surveyors must be informed when facilities are not referring and must discuss this with management when they conduct the annual certification survey.
- The facility must be cited for not asking the question as part of the discharge planning regulations. In addition, staff in such homes must be retrained by the NYS.

Recommendation Five: Improve the State Role (cont'd)

NYS must gather information on what types of residents are being referred.

- Are facilities inappropriately looking at feasibility and not referring certain types of residents such as those with a developmental disability?
- NYS should look specifically at nursing homes with a DD population.
- Numbers of referrals from each nursing home should be publicized on the State's website.

Recommendation Five: Improve the State Role (cont'd)

- The State must develop written material for nursing homes, LCAs, managed long term care plans, transition centers and residents/families.
- Material must be distributed widely and put on the State's website.
- Consumer material must be required to be given out routinely in the nursing homes and made accessible in the nursing homes where residents congregate.
- Consumer materials should be available in alternate formats.

A Brief Review

- What are the differences between PASRR and MDS?
- What have been the experiences with Section Q for People with Disabilities in nursing homes?
- What do advocates say about Section Q?
- What do facility staff say about Section Q?
- What do Local Contact Agencies and Long Term Care Ombudsmen say about Section Q?
- What would you recommend to improve Section Q for people with developmental disabilities and others?