



CID-NY

Manhattan
841 Broadway
Suite 301
New York, NY 10003
212/674-2300 Tel
212/254-5953 Fax
646/350-2681 VP

Queens
80-02 Kew Gardens Rd
Suite 107
Kew Gardens, NY 11415
646/442-1520 Tel
347/561-4883 Fax
347/905-5088 VP

www.CIDNY.org

Center for Independence of the Disabled, NY

Wanting to Go Home...

Waiting to be Asked:

**Section Q and People with
Developmental Disabilities**

**by
Cynthia Rudder, PhD.**

**Susan M. Dooha, J.D.
Executive Director**



A United Way Agency



Manhattan
841 Broadway
Suite 301
New York, NY 10003
212/674-2300 Tel
212/254-5953 Fax
646/350-2681 VP

Queens
80-02 Kew Gardens Rd
Suite 107
Kew Gardens, NY 11415
646/442-1520 Tel
347/561-4883 Fax
347/905-5088 VP

www.CIDNY.org

Center for Independence of the Disabled, NY

INTRODUCTION

I. EXECUTIVE SUMMARY

It has been more than a quarter of a century since the shocking conditions in which people with developmental disabilities were institutionalized were exposed and Willowbrook was subsequently closed. More than 30,000 New Yorkers with developmental disabilities have moved to less restrictive settings in the community. The State is working to bring people with developmental disabilities out of developmental centers, where more than a thousand reside. Finally, as of the first quarter of 2014, there were 1,057 people with developmental disabilities in New York State's nursing homes.¹ The Office for Persons with Developmental Disabilities (OPWDD) agreement with the Centers for Medicare and Medicaid Services (CMS) for the period of 2013-2016 entails transitioning 875 people to less restrictive settings, including 100 residents from skilled nursing homes to community-based housing.²

The State's ability to achieve its deinstitutionalization goals would be supported by effective administration of the federal survey requirement that reflects the nation's long-term care policy: Section Q of the federal government's assessment the Minimum Data Set (MDS). While other tools exist to facilitate deinstitutionalization, the State's agreement with the Federal Government and its Money Follows the Person (MFP) program contemplate that the Section Q referral question has a role in the deinstitutionalization of people with developmental disabilities. With the initiation of a new phase in New York State's MFP program, there is a new opportunity to consider the current approach to implementing the Section Q referral question and whether and how it might be improved.

However, the Section Q process does not appear to be working as conceived by the U.S. Department of Health and Human Services or advocates who pressed for the creation of this lever to help individuals transition to the community. In particular, it is not working for those with developmental disabilities.

- Many nursing home discharge planning staff are not asking the Section Q referral question;
- Many discharge planning staff assume that people with developmental disabilities will not understand the question;
- Many discharge planning staff are concerned about family members or individuals being upset;
- If nursing home staff ask the question—a referral may not be made if the staff determine that discharge is not feasible;
- Ombudsmen are rarely involved;
- The roles of the different participants are not understood;
- There is little State training and oversight.

Stakeholder surveys and interviews reveal a strong concurrence among all the stakeholders that the process should be improved.

People with developmental disabilities and their advocates pointed to a need to increase understanding and to provide training. Interviews with people with developmental disabilities who have come out of nursing homes and their advocates confirmed what social workers/discharge planners and others told us: that nursing home staff need training to understand their responsibilities and the requirements of Section Q; that many do not know how to work with people with developmental disabilities and do not know about resources available in the community. People with developmental disabilities consistently told us that the staff either did not ask the question, or told them they could not get what they needed in the community. *"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."*

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 –"*. There needs to be better training (about working with people with developmental disabilities for the people asking the question).

Local contact agencies (LCAs) told us that they were not getting referrals; that staff at nursing homes were not asking the question; and that staff in nursing homes didn't think that 'their' residents were able to live in the community. In many cases, LCA staff said that they felt most facilities are not even asking the question. *"We only get referrals from about 25% of the nursing homes in our catchment area."*

Best practices identified in states where the Section Q referral process works gave us cues for improvements in New York. In depth interviews with states that have done well with Section Q showed that they had pinpointed potential problems with the process early on. In order to deal with those problems, states that did well ensured that there was buy-in by all stakeholders, bringing them together from the beginning. Nursing home staff and local contact agencies were well trained about the law, Section Q requirements, roles of various participants and about resources in the community; and educational materials for all participants – consumers, nursing home staff, local contact agencies, ombudsmen and families – were developed and available at each contact point.

As we put all of the pieces of our research together – the surveys of stakeholders and the studies of states' best practices – recommendations for changes in New York State became clear. In different settings and in slightly different ways, each stakeholder group confirmed the following gaps and areas for change and improvement.

We recommend:

- Federal consideration of having a neutral party ask the referral question;
- Development of regulations specifically relating to the question and referral;
- Stakeholder involvement;
- Coordination;
- Communication;
- Ombudsman involvement;
- Training; and
- Monitoring.

II. OBJECTIVES

We focused on how Section Q's referral question is working for people with developmental disabilities in New York City. The project goals are: to evaluate the current New York State process for complying with Section Q; to make recommendations for application to people with developmental disabilities; and to develop training for local organizations on how to help their developmentally disabled clients (and families) better understand Section Q and the referral process to improve their chances of receiving care in the most integrated setting.

III. STUDY ACTIVITIES

First, we identified stakeholders whose opinions are important to consider in an evaluation of Section Q as a tool to facilitate deinstitutionalization and in framing recommendations for its improvement. We elicited information and perspectives from the Department of Health Division of Long-term Care and Nursing Home Health Quality and Surveillance, the Office for Persons with Developmental Disabilities, Local Contact Agencies that receive referrals resulting from Section Q being asked, nursing home ombudsmen, and nursing home staff responsible for asking the Section Q referral question. We spoke with people with developmental disabilities and their advocates, including independent living center staff.

We gathered information from the various stakeholders on how well the current system in New York State is working for people with developmental disabilities through both on-line surveys and one-to-one in-person interviews, eliciting information on strengths and weaknesses as well as the ways to improve the system.

An on-line survey was developed in order to gather information from nursing home staff who are charged with asking the Section Q referral question. An email was sent to administrators of all New York City nursing homes (176) explaining the purpose of the survey and asking them to give the survey link to staff that ask the referral question. The three state provider associations (Leading Age, New York State Health Facilities Association and The Hospital Association of New York State) sent out notices of the survey to their NYC members. The survey was open from April 1 to April 30th. Reminder emails were sent out every two weeks. Fifty-nine nursing home staff responded. Although we stated that the survey was only for New York City nursing homes, of the 59 who responded, at least two that we know of were from outside of New York City. Since the survey was confidential, no demographic information was gathered unless the respondent agreed to be interviewed. Thus, we discovered that two of those interviewed were from out of New York City. We decided to include their responses since their responses did not differ significantly from the other responses gathered. All respondents who agreed to be interviewed were interviewed in-depth by telephone for one-half hour to one hour each. Ten (10) individual respondents were interviewed for more details and two additional nursing home staff who had not responded to the questionnaire asked to be interviewed on the phone. The information from these twelve (12) interviews is included in the analysis. Although some findings related to individuals with developmental disabilities are based on smaller numbers, the findings are consistent with the overall responses and the cited findings involved a majority of these respondents.

We developed an on-line survey for the New York City LCA to reach those individuals who go into nursing homes to educate the residents who have asked to learn more about living in the community based on Section Q referrals. In order to clarify their responses, we interviewed the staff of the New York City LCA twice in half-hour to one-hour telephone interviews. In addition, eleven (11) representatives of seven (7) different LCAs in New York State, including New York City, were interviewed one-on-one by telephone. The New York State Ombudsman and the New York City Ombudsman were interviewed separately.

We interviewed three (3) individuals with developmental disabilities who had been institutionalized in nursing facilities. We interviewed seven (7) advocates for people with developmental disabilities. The interviews focused on effective communication strategies and barriers to communication.

Project staff researched programs run in many different states to identify those four (4) states with "best practices." The following states were identified: North Carolina, New Hampshire, Virginia and Minnesota. We collected written material from each state and conducted individual interviews with government officials and other stakeholders in each state.

III. Background

Most-Integrated Setting is the Nation's Long-term Care Policy

Over the past decade, the federal government and the states have increased efforts to remove barriers to community integration for people with disabilities and seniors. The motivations to do this included the twenty-five year old Americans with Disabilities Act³ (ADA), which provides that people with disabilities must have opportunities equal to those afforded

their non-disabled peers, and that they cannot be discriminated against because of their disability. Further clarification of those civil rights and how they applied to people with disabilities in institutions came through the Supreme Court’s *Olmstead* decision⁴ that confirmed the right of people with disabilities to live in the least restrictive setting. The government was also reacting to advocacy by the disability community to make implementation of these laws a priority nationwide and a reality for the thousands of people with disabilities who were still in institutions.

The United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to people with disabilities when (1) such services are appropriate; (2) affected people do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.

The Supreme Court explained that first, “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.” Second, “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.”⁵

As a consequence of the laws and court rulings, 44 states now have nursing home transition and diversion waivers meant to help people move from nursing home facilities to the community with programs and services.⁶ And other programs have been developed to help people with disabilities live according to their goals and abilities.

Another lynchpin of the effort to rebalance long-term care from institutions to the community and of the Office for People with Developmental Disabilities (OPWDD) Transformation Agreement is the Money Follows the Person (MFP) program.⁷ MFP creates LCAs that work with nursing home discharge planners to enable people on Medicaid who want to and who can benefit from community resources to transition to the community.

Section Q of the Minimum Data Set (MDS) Is Intended to Increase Transition to the Community by placing an Individual’s Choice to Move Home at the Center of the Process

When *Olmstead* was decided, ADAPT, a national grass roots disability rights organization, pushed for the Federal Government to do something with data that had been collected on whether people with disabilities could be transitioned out of nursing homes. This data had been collected as part of the Minimum Data Set (MDS) required of all nursing homes. Meeting and working with CMS, they were able to get modifications to the Participation in Assessment and Goal Setting (Section Q) questions of the MDS, as well as a process for responding to residents who wanted to transition to the community⁸. For the first time, Section Q included a question asking all residents if they would like to speak to someone about getting care in the community. “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.”⁹

Section Q now requires identification of *all* individuals interested in receiving information from an outside source, LCA, most of whom are involved in the MFP program to provide information about services and supports in the community and to help organize the transition to the community. Many of the LCAs are disability organizations.

The intent of all of the changes was to adopt an even more person-centered approach, placing the resident/family at the center of decision-making, giving individuals a voice and a choice while being sensitive to those who may be upset by the assessment process.¹⁰ Significantly, instead of staff deciding the feasibility of discharge, the “feasibility” question was removed. Nursing home staff are now required to ask a resident if s/he wants to speak to someone outside the nursing home about getting care in the community. The focus is on the resident’s opinions, not whether staff considers the resident to be a good candidate for return to the community; it does not guess what the resident might identify as a goal.¹¹

Once the resident (and/or family member) identifies an interest in more information about discharge from the nursing home and says yes to talking to someone about community care options and supports, the nursing home must refer the resident to an LCA. Facilities that have the capability to completely address an individual resident's needs for transition to the community do not need to make an LCA referral.^{12,13,14}

Section Q questions are to be asked upon admission, quarterly, on an annual assessment and at any significant change in the resident's condition unless the resident does not want to be asked and has said so. If the resident (or family member, or significant other if the resident is unable to understand or respond) states s/he does not want to be asked this question on every assessment, Section Q requires the nursing home to document this.¹⁵ *The nursing home should not assume that any particular resident is unable to be discharged.*¹⁶

The LCA is responsible for contacting referred residents and assisting with transition services planning. This mandate does not have a specific regulation attached to it and surveyors will not focus their review on resident referrals to the LCA unless there is a complaint. Surveyors are instructed only to evaluate whether comprehensive care planning is conducted appropriately using the information from the MDS.¹⁷

Ombudsman Role

CMS clearly describes the importance of including the state ombudsman in the MFP process and the Section Q referral process: "The Office of the State LTC (Long Term Care) Ombudsman is a stakeholder that should be included in the development and implementation of all MFP programs. They are a critical resource to provide information to the SMA (State Medicaid Agency) on how the Section Q referral and follow-up process is functioning and to handle consumer complaints should they arise. Any state that currently has an MFP Demonstration Grant program can request supplemental administrative funds to work directly with the state LTC Ombudsman. Examples of activities that the State LTC Ombudsman can assist with include: conducting outreach; providing information and educating residents/families of nursing facilities and consumers about community care resources; making referrals to LCAs; and resolving consumer complaints related to Section Q referrals and follow-up activities".¹⁸

The Section Q Process in New York

In 2010, New York State designated nine organizations to be the LCAs that handle all referrals from Section Q of the MDS. Nursing homes were not trained by the State in this new approach and were not given any update when significant changes were made in 2012 (such as the removal of the feasibility criteria). No written material was developed for nursing homes, LCAs or consumers to explain the new system and the consumer brochure developed by CMS was never given or required to be given out to consumers.

All LCAs were trained by the State in 2010. Quarterly meetings were held with Department of Health staff for about two years. After the initial training on the responsibilities of the LCA, they were directed to make up a referral form with cover sheet to be approved by the DOH. In addition, they had to report to DOH total referrals received each quarter and the number of MDS Section Q referrals.¹⁹ However, many LCA staff stated that they heard nothing from the State about the numbers of referrals they were receiving. They wondered if the State was reviewing their data. Few trainings or meetings have been held since.

In April, 2013, the State published a new request for applications for LCAs for both MFP and Section Q referrals. The new requirements for applicants change the current practice in two very important ways: (1) OPWDD will now participate in MFP and Section Q referral work with nursing home residents with developmental disabilities; and (2) there will be two components – Peer Outreach and Referral, and Transition Centers. Peer Outreach and Referral will be similar to the current LCA mission to educate and will involve the participation of peers who reflect the characteristics of the individuals being referred, and who, where possible, have themselves transitioned from an institutional setting into the community. In addition, Peer Outreach and Referral will now be required to assure that appropriate referrals are made to the Transition

Centers. Transition Centers will now be required to facilitate successful transitions of individuals into community settings with appropriate home and community-based services and supports to enable them to remain in the community.

Another Path: Preadmission Screening and Resident Review (PASRR)

Legislation enabling PASRR was passed prior to the 1990 ADA and prior to the Supreme Court's *Olmstead v. L.C.* in 1999. However, according to the PASRR Technical Assistance organization, the regulations that govern PASRR were written post-ADA and reflect the intent of that law.²⁰

The New York State Department of Health is the State Medicaid agency responsible for PASRR and has oversight of nursing homes. OPWDD is the agency responsible for PASRR Level II assessments of persons with intellectual/developmental disabilities in New York State.

As a process, PASRR has two core components. The first, Level I screen, is given to all nursing home applicants and identifies individuals who might have a developmental disability. The second, Level II evaluation, confirms a positive Level I or prior Level II; it determines whether placement or continued stay in the requested or current nursing home is appropriate; it also enumerates the services the individual needs, including services the nursing home can provide and services that must be arranged separately (so-called "specialized services").²¹

The PASRR evaluation includes verification of intellectual/developmental disability, as well as a review of whether the person is appropriate for the level of care provided by the nursing home, and whether the person is in need of specialized services or services of a lesser intensity. Although the individual participates in the evaluation, the determination of placement is made by the PASRR coordinator.

PASRR and Section Q Ask Different Questions

While PASRR has the potential of helping to transition developmentally disabled individuals from the nursing home into the community, Section Q referral question is more in line with the *Olmstead* decision since it gives the control to the individual rather than the professional. Where PASRR is conducted by a professional who does take into account feasibility and makes the determination where to place the individual, the Section Q question asks the resident directly where s/he wants to receive care. Once the individual says yes to receiving care in the community, it is up to the State to plan the transition to the most integrated and independent setting possible unless there is a legal impediment. If there is a legal impediment, it is up to the State to try to overcome that impediment.

OPWDD has said that to harmonize Section Q with the PASRR process, OPWDD will be notified of a significant change in the person's condition while in a nursing home that would trigger an inquiry of whether a community placement is available, but also the PASRR Coordinator would be notified of a "yes" on Section Q—that an individual wants to return to the community. OPWDD has stated that procedures for aligning these questions have been developed.

IV. What Is the Status of Implementation of Section Q in New York State

The Nursing Home Perspective

Nursing home staff survey responses²² and subsequent nursing home staff interviews²³ found that the majority of nursing home staff (56.1 percent) do not believe it is helpful to ask people if they want information on living in the community and many are not asking the question at all. Most of these respondents (80.6 percent) believe that it is not a valuable question because discharge is not feasible, will be a waste of time and raise false hopes. Many (74.2 percent) believe that asking the question is not going to be understood by "some residents" with developmental disabilities and it will be harmful and upsetting to individuals and their families. Others convert the question into whether they themselves believe that discharge is feasible because of the individuals' disabilities or lack of community resources. As a result, many say that they don't ask the question or don't refer. Of those who do ask the question, most do not ask anything further if the resident responds no, not trying to find out what the true desires of the resident are and if there are obstacles that could be overcome.

The large minority (42 percent) who support asking the question most often say that it is valuable because they get to know their residents better by asking (68.2 percent of those responding that the question is valuable).

Nursing home discharge planning staff are not necessarily asking Section Q

Perhaps as a consequence of this, the nursing home discharge planning staff are not necessarily asking the Section Q question or are not sending in responses if they do ask. Their answers indicate a need for training concerning the law, the purpose of Section Q, or the philosophy of self-directed care as well as better monitoring and oversight by the state.

"I disregard most of the responses you get - I add them in - many times they might say they want to go home, but they are confused or family doesn't want it. I will know from working with team, family, etc. before asking the question. I have had very few referrals - even if they said yes," 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."

"Most of us don't always interview the resident - no time - 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."

People with cognitive or intellectual disabilities won't understand

There is widespread conviction among those that did not believe the question to be valuable that the question will not be understood by some individuals with intellectual or cognitive disabilities (74.2 percent). When the question is asked, "Have you asked the question of any residents with a diagnosis of developmental or intellectual disability?" only 54.9 percent of discharge planners say they asked the question of residents with a diagnosis of developmental or intellectual disability.

"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."

People who are asked will be difficult

Respondents that had problems with individuals with cognitive or intellectual disabilities overwhelmingly (72.7 percent) believe that residents are difficult to deal with when they have different goals from family members/guardians. Perhaps this is one of the reasons that one in four believe that the question should not be asked as a result.

"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 persevere on the possibility, creating disappointment when it doesn't work out."

Family 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. It seems as if the respondents believe that family concerns trump the resident's desires and goals.

Over 34 percent believed that it might help to talk to family members/guardians first. Many felt that they would get a great deal of resistance from the resident’s family members – again it seems that family concerns are outweighing the resident’s right to decide on where they want to live and receive services.

"Some family members are angry that I am asking the question; they tell me that the resident has to stay in the facility."

"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..."

"We need to speak with family if resident is often confused to investigate whether discharge is a realistic opportunity."

"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."

"I have two, one with a legal guardian. I know he wants to leave; I don't have to ask the question. The other one has no resources in the community and doesn't interview well."

Community resource limitations pose barriers to discharge

A large minority (40 percent) of the nursing home discharge planning staff who have asked Section Q of residents with developmental disabilities report that they have had problems. In part, this is because a large number of the nursing home discharge planning staff who have asked Section Q of persons with developmental disabilities report that they are unfamiliar with community resources or find that community resources are inadequate to meet the needs of transitioning residents. They said that they do not know who in the community to contact for information.

"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 a sense of false hope."

"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."

"The State is closing down their housing - group homes, ICFs – the staff that would support their DD clients – there are not a lot and they are far away. When I first started working, the DD resident had their own case manager from DD who came every other month to do an evaluation and tell us what the resident needs. We don't have that anymore."

Ombudsmen Not Involved

Almost 80 percent of the respondents stated that the ombudsmen were not involved in the process.

What Can Be Done to Improve the System?

When all respondents were asked how to improve the system, many spoke of the need for training for nursing home staff and education for residents and family members so they can understand why the question is being asked, and support from supervisors.

The Local Contact Agency (LCA) Perspective

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.

Some nursing home discharge planning staff are not asking Section Q

In many cases, LCA staff said that they felt most nursing homes are not even asking the question. Most of those interviewed said that many nursing homes had never referred a resident. "We only get referrals from about 25% of the nursing homes in our catchment area."

Most said that social workers/discharge planners were either not asking the question or were manipulating the response. One interviewee said that some social workers/discharge planners 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."

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. One interviewee stated that when she discussed with a social worker that she is supposed to refer 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." The State is not monitoring whether the nursing home is asking the question or not. And without any accountability, nursing homes will not ask the question.

"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

When asked about the possibility of improving the Section Q response, LCAs cited the need for nursing home staff accountability for asking the question, monitoring to ensure that it is asked and that referrals are made, and education from the State for nursing homes about Section Q.

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.

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 of their rights to be asked the question as well as 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.

Prevention

LCA respondents also identified proactive steps prior to nursing home placement to help people before they are sent to nursing homes. “Put funds into the project to include going into hospitals to try to help residents get care in the community before they are sent to a nursing home.”

Long Term Care Ombudsman Perspective²⁴

Nursing home social workers/discharge planners are not asking the question or making the referral

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

She believes that if the resident says yes, the nursing home 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.” She strongly feels that social workers/discharge planners 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.

People with Developmental Disabilities and Advocates Perspectives²⁵

Individuals and advocates have guidance on asking Section Q

Ms. D has developmental and other disabilities. She had been in the nursing home for three months. She was so frightened by the thought of returning to the nursing home that interviewers for this study had to take a great deal of time to reassure her that nothing she said would endanger her living situation in her new home. She agreed to do the interview because,

“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.”

The nursing home staff assumed that because Ms. D was developmentally disabled, she could not understand them. And, although Ms. D was able to speak, she was listed on the records as non-verbal, thus, staff did not speak to her. Ms. D. stopped complaining and talking and became seriously depressed. She stopped eating.

Mr. R says that if someone answers yes to those questions, they should get help to plan leaving the home.

"Nursing home staff should ask the question kindly, gently."

Advocates first say that Section Q can't be asked alone. People with developmental disabilities need information on what else they could be choosing. They need an exploration—how would meals be different, getting dressed, and other activities of daily living.

People want Section Q to be asked

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.

"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."

Individuals and Advocates say that family members need education

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.

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

"Family should not speak if a patient can talk for himself."

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; that is my 'privilege', 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."

Education 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.

"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. But there are a whole bunch of variables including issues that come up that have nothing to do with a person's disability that affect their ability to live on their own."

"Nursing home staff need training on how to ask people question. 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."

Advocates say that people with developmental disabilities are capable and have a diverse set of skills.

"People have more self advocacy skills than the nursing home staff think. You could be asking questions like, are you taking your own meals, are you getting dressed by yourself, and what do you like to do? Many are already choosing things, advocating for what they want. Staff could then ask questions like, what else would you like to do during your day? Where would you like to live?"

"A lot of time these things are clinically done, and it's a checklist rather than helping people in the exploration process. Nursing home staff need training on philosophy of choice and person-centered approaches."

V. WHAT OTHER STATES HAVE TOLD US²⁶

Involve all stakeholders from the beginning

The state programs we looked at began by bringing together all of the stakeholders to make sure that all staff involved in working with residents "bought in" to the idea that nursing home residents can be transitioned back to the community. Committees were formed to develop the referral and transition process and training curriculums. By including all parts of the state government involved in the program, committees were able to create better coordination among state offices. This is crucial and may have eliminated potential problems. In some cases, this permitted an early understanding of various stakeholder concerns so they could be dealt with in the trainings.

Coordinating all state entities

Most of the states worked hard to make sure there was coordination among state offices and key players. 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." The Statement of Understanding outlines the roles of all the stakeholders, has a workflow chart, gives the rationale for the changes to Section Q and lists all roles and responsibilities. Virginia also has an "Authorization to Use and Exchange Information," to explain how to share information on a resident with all needed agencies, including Centers for Independent Living, so that they can work together to jointly provide or coordinate services for individuals with complex needs. In April, 2012, the State decided it needed someone at the State Medicaid Agency to coordinate with the other state agencies, providers and community organizations such as centers for independent living and appointed a State Section Q Coordinator. The Coordinator educates nursing homes, problem solves, takes family calls, etc. New Hampshire started a team of professionals that meet to help individuals transition to the community. The team includes the Choices for Independence staff person, the independent case manager (every individual on Medicaid has a 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 to be by the resident.

Participation of the ombudsman

All of the states involved the Ombudsman Office both from the beginning as well as during the implementation. In North Carolina, the State Ombudsman's Office developed a memo for ombudsmen on how to work with the LCAs. In Virginia, in addition to being part of the original group developing the materials and protocols, the local ombudsmen made contact with the nursing homes they worked with and discussed the changes. In New Hampshire, the State Long Term Care Ombudsman participated in the development of the 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. 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).

Communication

Developing readily accessible written materials outlining process and rationale

All the states developed materials for stakeholders that delineated the different roles and clearly defined the process; these materials were posted on state websites. Most of the materials were focused on the LCAs and the nursing home staff, and most focused on the referral process. However, New Hampshire's manual also gave nursing homes tips on how to conduct discharge planning and how to relate to the ombudsman. North Carolina, for example, also developed a "Personal To-Do List for Transition Next Steps" for residents/family members and a brochure for residents/family members on their rights. In addition, the materials included ideas for nursing homes on how to use the brochure with their residents.

New Hampshire stakeholders (including nursing home management and staff) had an active role in developing plans for the referral process and related deliverables. Their participation in the creation of the training curriculum led to an ownership in the new Section Q referral process. The on-going outreach to nursing facilities during the development stages of the referral process, which consisted of sharing policy drafts and soliciting input, promoted greater support and buy-in of the referral process and ultimately, successful trainings. Additionally, these interactions provided an insight into nursing home training requests and needs.

In addition, New Hampshire developed a video that can be streamed on line. The video is another way to help explain the process; it can be viewed at any pace and remains on line. 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

Training all stakeholders

"Education must be constant. Referrals do go up when training is done." (Virginia)

All of the states developed training clearly describing the different roles. Training focused on both the process and person-centered care and resident choice. A few of the states continue to conduct trainings. Most agreed that constant training is crucial. 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, those providing counseling must have a minimum of a Baccalaureate degree from an accredited program of Social Work, Gerontology, Nursing or a related human services field. In addition, they must be able to encourage self-empowerment and recognize the right of people to make their own choices. They receive required training and must have a Boston University Certificate in Aging. In North Carolina, LCAs must be "Certified Option Counselors," in order to make sure that the LCAs 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 of the states focused on the rationale for Section Q: giving the resident a voice and a choice; placing the resident at the center of decision-making; and introducing person-centered care. Thus, training often focused on person-centered care as well as the specific referral process. New Hampshire's on-line 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.

Need to focus on individuals with developmental disabilities

Minnesota and Virginia are looking at this issue. Minnesota has begun a Disability Link Line to focus on people with disabilities. However, it adds no new funds; counselors must talk to the nursing home residents by phone, not on-site. Virginia consumers believe that the present system is failing individuals with developmental disabilities.

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 from the MDS 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 and have gone to “as many nursing homes” as possible to discuss any inconsistencies.

The State hopes in the near future to begin 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. 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 North Carolina looked at regions of the State where there were zero referrals. They went to those regions to offer training. This year, they have a new initiative called, “inreach,” as opposed to outreach. They are requiring the LCAs to go into two nursing homes in their region (where there have been zero referrals) to talk to staff (starting with the administrator) about the intent of the question and to help them understand their role and how they can work together.

In Virginia, all referrals are entered electronically into the State’s web portal. The State Section Q Coordinator receives reports of all referrals quarterly. She tracks them and if she finds that some nursing homes are not referring residents, she calls them and asks them if they understand what the purpose of Section Q is and how to conduct the process. She deals with them one-on-one as well as through training. Last fall, the Coordinator started to look at the corporations that own some of the facilities in the State. She decided to talk directly to the individual in the corporation who works with the social workers/discharge planners about Section Q and its importance.

Need for survey and certification to take a more proactive role

In at least two of the case study states, the survey and certification professionals do not specifically look to make sure the nursing home is complying with the Section Q mandate. They will look into any complaint or, if the issue comes up in an interview or other task, they will investigate. Although the federal government has mandated that all nursing homes must ask the referral question, there is no regulation attached to this mandate and there is no specific survey task focused on this question, so it is difficult to get the survey and certification staff to make this a priority.

Need for more serious punishment 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)

In fact, non-compliance brings little sanction to a nursing home. Since there is no regulation attached, the only way a citation can be issued is if the non-compliance is related to other regulations. In addition, 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.

VI. RECOMMENDATIONS

Some nursing home staff do not ask the question at all. Over half of those who did not find the question valuable said that they believe that some residents with cognitive or intellectual disabilities do not understand the question and should not be asked.

The recommendations below are made based upon the findings from all of the stakeholders as well as our state case studies. The state case studies indicate a number of common features that would seem to support success: (1) involving all stakeholders from the beginning; (2) developing readily accessible written materials outlining process and rationale; (3) mandating significant qualifications for LCA staff; (4) training all stakeholders; (5) focusing on person-centered care; (6) careful state monitoring the system; and (7) coordinating all state entities.

Recommendation One: A Neutral Party Should Ask the Referral Question

It is clear from the findings that the major problem with making the system effective lies in the role of the nursing home discharge planner and how and whether they ask the referral question and whether they make referrals. It may not make sense for nursing home staff to ask the referral question. This may be a conflict of interest because they may be pressed to keep their beds occupied; they may be too focused on protecting their residents and averse to permitting them to make their own choices; they may not feel they have the time to devote to helping residents with developmental disabilities transition out of the nursing home. Thus, we suggest that the Federal government consider having a neutral party ask the referral question. In addition, because there is no regulation attached to the mandate to ask the question, state surveyors find it difficult to cite facilities for not asking the question. The Federal Government should develop regulations specifically tied to the asking of the referral question and surveyors must be required to review this on each annual and certification survey.

Recommendation Two: Bring all stakeholders together

It is clear from the findings that many nursing home discharge planners do not understand the national policy that underlies Section Q or how to ask Section Q. They do not have training or support for asking it of people with developmental disabilities.

It is crucial to bring representatives of all stakeholders together to both explain Section Q as well as to identify ways to overcome problems with asking the Section Q question. This group should include people with developmental disabilities and advocates; representatives of nursing home discharge planners; Local Contact Agency representatives; Department of Health, Office of People with Developmental Disabilities, State and Local Ombudsmen.

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

Nursing home discharge planners need to understand the importance of the Section Q referral question, their role, the role of the LCAs and the community resources available. They need to know more about the rights of residents, person-centered planning, and have assistance understanding the skills and abilities of people with developmental disabilities. Training must include 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 should be involved.

Recommendation Five: Improve the State Role

There is a need for New York State to better monitor the nursing homes to ensure that the Section Q referral question is being asked and that referrals are being made. The State must make monitoring and oversight a priority. First, the

State must gather data demonstrating which facilities are not referring residents. The State must be required to meet with those nursing homes that are not referring residents to explain to them the need to refer and to explain their role. State surveyors must be informed when nursing homes are not referring and must discuss this with management when they conduct the annual certification survey. The nursing home 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 State. Second, the State must gather information on what types of residents are being referred. Are nursing homes inappropriately looking at feasibility and not referring certain types of residents such as those with a developmental disability? The State should look specifically at nursing homes with a developmental disability population. Numbers of referrals from each nursing home should be publicized on the State's website.

The State must develop written material (with input from all stakeholders) for nursing homes, LCAs, managed long term care plans, transition centers and residents/families. This 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.

ACKNOWLEDGEMENTS

The research for this report was supported by the New York Community Trust. The authors would like to thank the many individuals who participated for their willingness to share their time, their experiences and their knowledge, without which our report could not have been written. First we want to thank the people with disabilities and advocates, including independent living center staff, who shared their Section Q nursing home experiences with us. We also want to acknowledge the many nursing home discharge planners and social workers in New York City (and the three state-wide provider organizations who encouraged their members to fill out our on-line survey) who participated in our survey and interviews. And, we are grateful for the participation of the Local Contact Agency (LCA) representatives throughout the state, and the stakeholders (state officials, ombudsmen, and consumer advocates) in the states chosen for our case studies. We would also like to thank staff from the Department of Health's Division of Long-Term Care and Nursing Home Quality and Surveillance and staff from the state Office for Persons with Developmental Disabilities for the information they gave us.

ABOUT CIDNY

The Center for Independence of the Disabled, New York's (CIDNY) goal is to ensure full integration, independence and equal opportunity for all people with disabilities by removing barriers to the social, economic, cultural and civic life of the community.

In 2014, we helped over 15,000 people take control of their own lives by offering information, education and advice to individuals struggling with poverty, housing, barriers to health care coverage and access, nutrition, education, and work. We help apply for services and supports, navigate complex systems and advocate for consumers when things go wrong. We provide technical assistance to public and private entities to improve their disability literacy. We guide lawmakers on sound public policies that will foster equal opportunity.

In the last five years, CIDNY has been party to successful lawsuits that seek to protect the civil rights of people with disabilities. Our expert testimony and evidence helped win a lawsuit to ensure the rights of people with disabilities to vote independently and to travel throughout New York City in accessible transportation. Most recently, we were plaintiffs and won a landmark decision that directs New York City to provide an equal opportunity for people with disabilities to survive in disasters and emergencies by adhering to seven specific Memoranda of Understanding in planning for those events. Our success in these lawsuits is due, in part, to the data we collect and the analysis we provide about people with disabilities and the affect public policies have on our lives. This report will help policy makers, funders, and disability advocates as we continue to ensure the rights of all people with disabilities.

- 1 <http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report.html>
- 2 Since April 2013, 132 individuals have transitioned to the community. MFP Stakeholder Advisory Committee, June 18, 2014.
- 3 ADA of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990).
- 4 *Olmstead v. L.C.*, 527 U.S. 581 (1999).
- 5 http://www.ada.gov/olmstead/olmstead_about.htm
- 6 "Beyond Section Q: Prioritizing Nursing Home Residents for Transition to the Community," Brant E Fries and Mary L James, *BMC Health Serv Res.* 2012; 12:186. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3522008/>
- 7 Money follows the Person Rebalancing Demonstration,
- 8 Interviews with Mike Oxford, Director, Topeka Independent Living Resource Center and Bruce Darling, President and CEO, Center for Disability Rights, Rochester, NY, June, 2014. It is interesting to note that Mr. Oxford stated that ADAPT also tried to get a neutral third party to ask the resident if s/he wanted to speak to someone about getting care outside the community, but were unable to get that.
- 9 MDS 3.0 Section Q Implementation Questions and Answers (Q & As from July 6, 2011 to June 30, 2012).
- 10 MDS 3.0 Section Q Implementation Questions and Answers (Q & As from July 6, 2011 to June 30, 2012).
- 11 Ibid.
- 12 MDS 3.0 Section Q Implementation Questions and Answers (Q & A from July 6, 2011 to June 30, 2012).
- 13 Hunt, S.S, Changes in the MDS 3.0: For Long-Term Care Ombudsmen, September, 2010, the Consumer Voice.
- 14 Minimum Data Set (MDS) – Version 3.0, Resident Assessment and Care Screening, Nursing Home Comprehensive (NC) Item Set.
- 15 Ibid.
- 16 Ibid.
- 17 <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Community-Living/Downloads/mds-3-0-section-Q-implementation-q-a.pdf>
- 18 Department of Health & Human Services, Letter from Kathy Greenlee, Assistant Secretary for Aging and Cindy Mann, Director, Center for Medicaid, CHIP and Survey and Certification, November 3, 2010.
- 19 Interview with LCA representative.
- 20 Interview with staff of the PASRR Technical Advisory Group.
- 21 PASRR Instruction Manual
- 22 Appendix 2
- 23 Ibid.
- 24 Interview with NYC Ombudsman
- 25 Appendix 3
- 26 Appendix 1