

North Carolina

Bringing Together All Stakeholders: Strategies for Implementation

Before North Carolina implemented its process, it brought together a group of stakeholders (Steering Team) to develop a strategy for implementing the process for referrals from Section Q. Participants included the NC Division of Medical Assistance, the Ombudsman Program, the MFP Program, NC Health Care Facilities Association, NC Division of Vocational Rehabilitation, NC Division of Health Service Regulation (the MDS enforcement agency), Centers for Independent Living, Local Contact Agencies, Community Resource Connections (NC equivalent to ADRCs), Area Agencies on Aging, NC Division of Social Services, Disability Rights North Carolina, and NC Division of Aging & Adult Services.¹

This group met monthly to make decisions regarding the implementation of the MDS and to determine the designation of the Local Contact Agencies (LCAs). A subset of this group continues to meet quarterly with the purpose of creating additional structure for LCA activities and to formalize policies and protocols that govern how LCA organizations provide this service.²

Because the state understood the potential conflicts of interest for some nursing home staff, it focused on making sure that nursing home staff “bought-in” to the process. In order to allay any fears that the state wanted to close nursing homes, the state wanted nursing homes to understand that the LCAs are not focused on transitioning residents out of the home, but are focused on finding out what the resident may want including care in the nursing home, which some residents might choose. The focus was on resident control.

Developing Materials

Referral Response Toolkit

The state developed a detailed referral guide for LCAs and nursing homes.³ The guide includes flowcharts and directions for LCAs on how to conduct an interview, establish rapport and be an active listener. A detailed framework for conducting the interview is given to help engage the individual in an initial discussion. This guide also includes a flyer describing the LCA, Disability Rights of North Carolina, and how to contact them as well as other advocacy groups such as independent living centers. In addition, some information is given on how to find housing resources.

Creating protocols for collaborative work between ombudsman and options counselors

The State Ombudsman’s Office developed a memo for ombudsmen on how to work with the Options Counselors (i.e., those speaking to the residents). Examples given on ways an options counselor might interact with the long-term care ombudsman program are:

1. An ombudsman may refer a nursing facility resident to the options counselor, particularly if the facility is not being responsive to a request by the resident or ombudsman.

¹ Information from Lorrie Z. Roth, MBA, MHA, N.C. Department of Health and Human Services Community Living Coordinator, Planning, Budget and Systems Support - Division of Aging and Adult Services, January, 2014.

² Interview with State Ombudsman, January 2014.

³ http://www.ncdhhs.gov/aging/LCA_StepbyStep_Referral_Guide.pdf

2. If the options counselor encounters barriers with the facility, a referral for the ombudsman to assist with access to residents may be needed. For example, the facility is interfering with the options counselor's attempts to call or meet in-person with a resident.
3. General problems experienced by a resident may be expressed to an options counselor. In these instances, an options counselor may refer a resident to contact their ombudsman or may contact the ombudsman directly.
4. After the options counselor researches and provides information to a resident, the resident or options counselor may request help from an ombudsman regarding explanation of their rights.
5. An options counselor who receives a complaint regarding the relocation process can notify the ombudsman and coordinate for advocacy services on behalf of the resident.

Uniform Forms

North Carolina developed a number of forms (all of which are included in the toolkit described above):

(1) LCA Contact Checklist – Outlines the pre-visit contact with the facility with specific questions and tasks such as when the best time to visit, or what is the financial status of the resident, or if there is a guardian, etc.; specific questions to ask the resident when they do meet; post visit tasks such as gathering additional resources; and follow-up tasks (see appendix for a copy of this form) .

(2) Facility Communication Form – Lets facility know when contact has been made with a resident and the outcome.

(3) Personal To-Do List for the resident if the resident wants to pursue transitioning to the community.

Local Contact Agencies are the triple As (Area Offices on Aging). North Carolina pays them specifically for their work with Section Q referrals. The LCAs are required to be objective and to help the resident (and family/guardian) understand their options. If a resident (family/guardian) wants to pursue transition to the community, the LCA will refer the resident to another organization that does transitioning (if their own organization does not do such work) such as the Independent Living Centers.

Training

LCAs Must Be Certified Option Counselors

North Carolina requires all local contact agency staff that respond to Section Q referrals to be certified as "Option Counselors." This requirement is in order to make sure that the LCAs know how to be "person-centered" and objective, letting the resident make the decisions, "Options Counseling" is a person-centered, interactive and decision-support process. The main purpose is to help individuals identify and understand their needs.

Options Counseling includes:

- listening to the individual express his/her preferences, values, service needs, and circumstances;
- engaging in conversation for a joint exchange of information and possible options that are tailored around the stated needs and preferences;
- providing support that leads the individual to make informed choices about long-term services and supports;
- connecting the individual, when it is his/her choice, to public/private services and/or informal supports;
- following-up with the individual with the ultimate goal to support the individual to live in his/her community of choice.

Options Counseling involves building relationships with individuals and helping them to identify their goals and preferences and weigh the pros and cons of their options. It includes the needs of both aging and disabilities populations.

Desired outcomes of Options Counseling include:

- individuals and families make service and support choices that fit well with their needs, goals and preferences – even as these change over time
- individuals achieve or maintain a high degree of independence and control in their daily lives
- individuals and families are able to get the services and supports they need and are better able to make good use of their own resources over time.

Training of LCAs

Options Counselor Training

Some of the training is web-based such as: information on Medicare, Medicare supplements, Medicare Advantage, Medicare prescription drug plans, long-term care insurance and other health insurance concerns. Other training involves on-site participation. The “Person-centered Thinking (PCT) training is a two-day on-site event⁴ and involves interview skills and consumer empowerment as well as cultural competency and health literacy and systems advocacy.⁵

Disability Training

The state has also contracted with Disability Rights North Carolina to conduct a one day advocacy training as part of the required training. This training includes: overview of laws affecting people with disabilities such as the American with Disabilities Act of 1990; Olmstead; Fair Housing Act and North Carolina’s Protecting Act, among others; guardianship; and a legal definition of “incompetent.” Much of the day is spent on motivational interviewing and role playing. The training stresses that motivational interviewing is collaboration between the counselor and the client; involves drawing out the client’s ideas about change; and emphasizes the autonomy of the client. Participants are given help in how to counsel with questions that can be asked.⁶ Examples of the role playing, where one person plays the counselor and the other the client, include⁷:

1. Sam is a 41-year-old man with moderate developmental disabilities. He has no brothers and sisters. He had been living with his mother until her death a month ago. Since her death, Sam has been staying with Charles, a close friend of the family who agreed to take care of Sam for a short period of time. Sam’s mother was his guardian. No substitute guardian has been appointed.

Participants were asked to develop an outline of questions they would use during their first meeting with Sam using the principals of motivational interviewing.

⁴ Options Counseling General Information, NC

⁵ Options Counseling Curriculum, NC

⁶ Options Counseling, Disability Rights North Carolina

⁷ Options Counseling Training – Practical Exercises

2. Roberta is a 32-year-old woman living in a nursing home. Roberta has a spinal cord injury. She has lived in the nursing home for 2 years. She moved into the nursing home after a car accident left her paralyzed without use of her legs, arms and hands. She was removed from the trach tube six months ago.

She is generally upbeat about her injury but has moments of anger. She cannot perform any daily living activities without assistance. She is using a wheelchair owned by the nursing home. She currently is not receiving any scheduled physical or occupational therapy.

Before the accident, Roberta worked as a hostess at a local restaurant. She enjoyed gathering with friends on the weekends, making quilts that she sold for extra money, and going to movies. At the time of the accident, she was living alone in second story apartment with no elevators. She currently has no income other than SSI.

Roberta's family lives in a rural area approximately 3 hours from the nursing home. Her father is deceased and her mother is in her 70s. She has one sister who lives at home with her mother. Roberta's mother is willing to have Roberta live in her home.

The participants were asked to split into groups of two – one person will be "Roberta" and the other person will be the "Options Counselor". They were asked to begin developing an action plan with Roberta.

Disability Rights North Carolina developed a web page where individuals could post information and where forums could be created to discuss the issues raised at the training. In addition Disability Rights urged anyone who needed any help to call.⁸

NC spent the last few years working to get the entire state (originally about 38 percent of the state had LCAs in their region) covered by appropriately trained counselors. During this same timeframe NC created documentation and training for the counselors to use and participate in. At this point NC covers 100 percent of the state with Certified Options Counselors, or Counselors-in-training, providing the LCA function to Skilled Nursing Home Residents upon request.

Other Training

The original Team went around the state conducting many trainings for LCAs and others. These trainings were focused on Person Centered Care Transitions. The training was open to all professionals working with transitions including: Nursing Home Administrators, Social Workers, Nurses, Ombudsmen, and Centers for Independent Living, Vocational Rehabilitation Independent Living, Arc staff, and Information & Assistance Specialists among others. Topics included: Understanding the Nursing Home's Responsibilities; the Local Contact Agency Role; and Money Follows the Person.^{9,10}

⁸ Interview with Disability Rights staff, January 23, 2014.

⁹ Person Centered Care Transitions: Introducing Resources and Tools for Effective Discharge Planning, Flyers, August 2011.

¹⁰ See, power points: The Local Contact Agency: Exploring Options for Community Living ([LCA & MDS Q region m \(1\).pptx](#)),

Training of Ombudsman

The State Ombudsman had several sessions in a round table format with NH licensure and certification representatives who explained the requirements under CMS Section Q. In addition regional ombudsmen had training by the division of medical assistance staff laying out the roles of the LCA, as well as an all day training that included a description of the core roles and responsibilities as part of an effort to clarify programmatic differences and points of collaboration. NC regional ombudsmen may participate on a local interdisciplinary LCA team.

Monitoring the Process

North Carolina has 430 nursing homes with 43,158 beds. At this point they are focused on making sure that the management of the nursing home has “bought into” the whole concept of the Section Q question. Thus, while it has conducted training around the state over the last few years, most of the staff attending from nursing homes have been discharge planners who are mandated to ask the question. In the past the Team had looked for regions where there were zero referrals. They went to those regions to offer training to the whole community. 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 understand their role and how they can work together. One of the regions is starting to help nursing homes provide options counseling themselves¹¹.

The decision of when to go out is left up to the LCAs. To date, about one percent of the nursing home residents have been referred. There is no attempt at this time to look at what kinds of residents are being referred to analyze whether only certain types of residents are being referred such as those who are new admissions or those who are less frail, etc.

In the future, they hope to do inreach to resident councils so residents will know they should be asked the Section Q question; they need to understand their rights.

Resident Control

Each resident is given a “Personal To-Do List for Transition Next Steps” if they want to know more about how to pursue moving back to the community.¹² This includes the LCA counselor’s name and phone number. The counselor helps the resident fill out the form.

The state urges LCAs to meet with the resident alone for the first visit and to ask the resident if they will permit a family member to be at the second visit. The resident is the one whose needs are elicited. The family is, or course, important for many transitions to the community.

Nursing Home Training

How the nursing home staff ask the question is crucial. It is here where the referral starts. There seems to be little training on how nursing home staff should ask this question. The licensing and certification division of the state conducts overall training for providers on the MDS. The state does not train nursing home staff in how to ask the question; it trains only in understanding the referral process and the different roles involved. State certification staff indicated that the nursing home staff must ask the

¹¹ Information from Lorrie Z. Roth, MBA, MHA, N.C. Department of Health and Human Services Community Living Coordinator, Planning, Budget and Systems Support - Division of Aging and Adult Services, February, 2014.

¹² Personal To-Do List for Transition Next Steps.

APPENDIX 1

State Case Studies

question **exactly as listed** (emphasis added) on the MDS. The state feels that the training involving how questions should be asked is up to the nursing home.

One state agency is starting to develop an educational module for mentally ill residents. In the future, it is possible that they might develop one for the developmentally disabled.

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Minnesota

Building Upon an Established Program

Minnesota developed an initiative in 2009 called, *Return to Community*. Section Q referrals were folded into this initiative. Passed during the state's 2009 legislative session, *Return to the Community* is targeted toward private pay nursing home residents who have expressed a desire to *Return to the Community* and have the resources and supports to assist with the transition. *Return to Community* works to help to change the mindset that nursing homes are the best place for individuals who need long-term care and respects people's preferences for living and caregiver arrangements. One of its unique features is that it provides a five year follow-up after nursing home discharge. *Return to Community* is targeted to nursing home residents who are early in their nursing home stay.¹³

Of course Section Q referrals target all residents, early or late in their nursing home stay. Minnesota felt it was able to easily implement the Section Q referral protocol due to two strategies that had been implemented prior to the MDS Section Q changes: The *Return to Community* initiative, which requires the Senior LinkAge Line® to provide statewide in-person assistance to private-pay nursing home residents who want to return to a community setting and the requirement that all Senior LinkAge Line® specialists have expertise in providing Long Term Care Options Counseling.¹⁴ This effort is intended to work closely with nursing facilities to support the discharge planner in helping the consumer *Return to the Community*.¹⁵ Follow up assessments are conducted for five years with the individuals who are transitioned from the nursing home. "Our whole system is comprehensive – transition is core to all the other things going on. When Section Q was mandated, we had a strong infrastructure in place."¹⁶

Developing *Return to the Community*

When *Return to the Community* began, the state held a three-day retreat and brought together all stakeholders - nursing homes (administrators, discharge planners, social workers, and ombudsmen), representatives of centers for independent living, AARP and the consortium for persons with disabilities. Using a business development approach (i.e., business process modeling, business process mapping), the group developed the process giving feedback on all developed materials over time. Business process mapping helps to generate consensus, ensure consistency, identify any duplication and makes the roles of all clear. It helps to document, understand and improve various processes.¹⁷ The group also developed many materials for the *Return to Community* initiative.

***Return to Community* Booklet**

This booklet is given to all consumers who receive in-person assistance from a Community Living Specialist in the nursing home. It describes the initiative and lets consumers know that people can leave the nursing home and successfully return to their house or apartment. It describes that the service is provided by Senior LinkAge Line®. These experts can discuss services and supports in the local

¹³ See, <http://www.mnaging.org/en/Advisor/RTCI.aspx>.

¹⁴ Senior LinkAge Line® Community Living Specialist and Designated Client Services Center Protocols, Version 6.0, April 1, 2014.

¹⁵ Letter to Facilities, March 2014.

¹⁶ Interview with Dawn Simonson, ED, Metropolitan Area Office on Aging, March, 2014.

¹⁷ Interview with Krista Boston, Director of Consumer Assistance Programs, Minnesota Board of Aging and Darci Buttke, *Return to the Community* Coordinator, Minnesota Board on Aging/Department of Human Services, March 2014 and see, <http://www.modernanalyst.com/Resources/Articles/tabid/115/articleType/ArticleView/articleId/1728/5-Key-Benefits-of-Business-Process-Modeling.aspx>.

community that may be available for people interested in living options outside the nursing home. It is not, however, focused on Section Q referrals.

Return to Community Brochure.

This brochure is given to all new admissions to a nursing home. It describes the service and urges nursing home residents to begin planning to return home.

Nursing Facility Letter - March 2014

This letter to administrators explains the *Return to the Community* initiative and explains that the Senior LinkAge Community Living Specialists receive referrals not only from a list provided by the Departments of Human Services, which focuses on those early in their nursing home stay, but also from positive responses to questions on Section Q of the MDS. The letter goes on to explain the process for Section Q referrals. It lets facilities know that they should give each person admitted to their facility a copy of the *Return to Community* brochure (which is attached to the letter and additional copies can be obtained at no cost).¹⁸

Senior LinkAge Line® Community Living Specialist and Designated Client Services Center Protocols

This protocol describes the initiative by listing the goals for consumers and Community Living Specialists as well as the key concepts of the program. This was originally developed by the stakeholder group.

Ads on Buses

According to a provider, there is lot of publicity about the Senior LinkAge Line on buses.¹⁹

Significant Requirements for Senior LinkAge® Line Counselors²⁰

Staff 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 They get required training and must have a Boston University Certificate in Aging.

Training

State staff conduct 'road shows,' explaining the *Return to the Community* Initiative. The audience for these trainings are nursing home discharge planners/directors of nursing/administrators, home and community-based service providers, Area Agencies on Aging, county case workers, managed care coordinators and assisted living facilities staff.

The Area Agencies on Aging (Senior LinkAge Line Specialists) provide trainings to nursing homes as part of their outreach. Trainings are also conducted by Minnesota Board on Aging/ Department of Human Services and Area Agencies on Aging on a regular basis, as needed based upon nursing home and discharge planner turnover - yearly at a minimum. State staff from the Minnesota Board on Aging and the Department of Human Services attend statewide conferences where nursing homes and assisted livings are in attendance. They also provide training as requested by the providers. The Community Living Specialists around the state all work with nursing homes in their areas to ensure they know how to submit the referrals through the online referral site.²¹

¹⁸ Letter to Facilities, March 2014.

¹⁹ Discussion with Darrell Schreve, Vice President for Health Policy, Aging Service s of Minnesota.

²⁰ 2013-2014 Standards and Assurances for the Senior LinkAge Line®

²¹ Email from Darci Buttke, *Return to the Community* Coordinator, Minnesota Board on Aging/Department of Human Services, September 9, 2014.

Monitoring

The Senior LinkAge Line is continuously monitored by the Minnesota Board of Aging to ensure that consumers are being followed up with or referred to their county case worker/managed care coordinator if the consumer is on public programs. Monthly dashboards are produced for leadership at the Department of Human Services as well as the Area Agencies on Aging. Individual staff dashboards began to be distributed in the Fall of 2013. The statewide dashboards that are provided to DHS senior leadership as well as the AAA Directors and are used to provide updates on numbers of consumers served as well as to identify trends in the data that may be happening over time. Many times the AAA Directors may share the monthly statewide dashboards with their own Boards or other community partners who may be asking about the service. They can also use the dashboards to monitor the workloads of the staff as the AAA version has additional staff information.

The individual dashboards are provided to the AAA directors for each of the Community Living Specialists who are employed by their office. They are very detailed: number of consumers assisted, outcomes of the follow ups they are conducting with consumers, protocol adherence for collecting releases of information, satisfaction results of consumers served etc. These are used for compliance to the protocol which includes multiple aspects.²²

MBA also conducts in-person site visits with each staff where shadowing occurs for 1-2 days to monitor protocol compliance (Senior LinkAge (LCA) compliance).

Ombudsmen Participation

The Office of the State Ombudsman was involved with *Return to the Community* from the beginning, participating in the retreat. They were part of a subcommittee formed from the larger group on resident rights. At this point their involvement is in partnering with the Senior LinkAge Line® to make sure that resident rights are paramount. If a problem with resident autonomy (relating to the Section Q referral question) is uncovered by the Senior LinkAge Line®, the ombudsman office might be called in with the resident's permission.

Monitoring

While it seems that one of the strengths of the Minnesota system may be the monitoring of the LCAs, it seems that an area needing improvement is the monitoring of nursing home compliance. State survey staff stated they did not specifically ask if the Section Q question was asked when on survey.²³ The names of nursing homes that are non-compliant and *are brought to their attention* (emphasis added) would be sent to the MN Department of Health or leadership at the Department of Human Services depending on the particular situation with the facility.²⁴ Since only 6 percent of the referrals are from Section Q,²⁵ the state might consider looking more carefully at Section Q referrals.

²² Ibid.

²³ Interview with Assistant Program Manager, MN DOH, Licensing and Certification, March 2014.

²⁴ Email from Darci Buttke, *Return to the Community* Coordinator, Minnesota Board on Aging/Department of Human Services, September 9, 2014.

²⁵ Presentation: Care Transitions through the Senior LinkAge Line®, Krista Boston, Consumer Information & Assistance Director, Minnesota Board on Aging/MN Department of Human Services, and Darci Buttke, Care Transitions Policy Analyst, Minnesota Board on Aging/MN Department of Human Services.

Need to Focus on Developmentally Disabled

"Whenever I see an individual with a developmental disability in a nursing home I wonder why they are there. Was screening done correctly? (Cheryl Hennen)

Minnesota has recently started a new disability line for individuals under the age of 60 in the *Return to the Community* initiative. The referrals would first go to Senior LinkAge line and then, if the individual is under the age of 60, they would be referred to this new help line. At this point there is no additional staffing or resources attached to this initiative, so staff cannot go on-site. They talk to them over the phone. They offer follow up and call the individual to find out if everything is working out. Staff from the Southeastern MN Center for Independent Living will be going out to nursing homes to put a "face" to the disability linkage line, to build relationships. At this point, they are not involved in Section Q referrals. "There should be two linkage lines responding to Section Q referrals."²⁶ The Deputy Director of the Ombudsman Office also believes that bringing the Disability Line into Section Q would be worth considering. "Whenever I see an individual with a developmental disability in a nursing home I wonder why they are there. Was screening done correctly? I do think that a Disability Line might have different resources available to guide DD individuals. However, there must be good coordination."²⁷

Need to Consider Long-Term Care Residents

Return to the Community targets residents who may be successfully transitioned from nursing homes, those in for shorter periods of time.²⁸ Consumers are identified through research based algorithm which predicts probability of discharge according to data from admission MDS assessment (residing in nursing home for 45 days, female, no mental health/Alzheimer's/Dementia, no serious behavioral systems, no diabetes, no end state disease, lower cognitive impairment, lower ADL dependence and no serious incontinence), desire to return to community setting (MDS Section Q), and not on medical assistance, which is handled by Money Follows the Person).²⁹ "We also must consider individuals who are in the nursing home for a longer period of time and are more challenging to transition. They also need to be able to be cared for in the least restrictive setting, if possible."³⁰

²⁶ Interviews with Vicki Dalle Molle, Executive Director and Julie Ronning, Disability Linkage Line Planner, Community Living Consultant, Southeastern MN Center for Independent Living, Inc. (SEMCIL), Choice Home Care, Inc. , April, 2014 and Lesli Kerkhoff, Community Supports Supervisor, Minnesota Department of Human Services, Disability Services Division.

²⁷ Interview with Cheryl Hennen , Deputy Ombudsman, Office of Ombudsman for Long-Term Care, September, 2014.

²⁸ Interview with Valerie Cooke, Nursing Facility Rates and Policy, MN Department of Human Services.

²⁹ Presentation: Care Transitions through the Senior LinkAge Line®, Krista Boston, Consumer Information & Assistance Director, Minnesota Board on Aging/MN Department of Human Services, and Darci Buttke, Care Transitions Policy Analyst, Minnesota Board on Aging/MN Department of Human Services.

³⁰ Interview with Cheryl Hennen , Deputy Ombudsman, Office of Ombudsman for Long-Term Care, September 2014.

APPENDIX 1

State Case Studies

Minnesota

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Virginia

Bringing Together All Stakeholders: Development of Implementation

An early work group (which started with a Money Follows the Person Group) was pulled together at a "MDS 3.0 Section Q Implementation Meeting." It brought together all of the stakeholders. Their charge was to set up a protocol and develop Section Q training. State Ombudsman and Centers of Independent Living were involved in the implementation and development of training. After a number of meetings, the large group broke up into a smaller work group (made up of state agencies) to continue the development process.³¹ The state continues to ask for information from all the stakeholders.

Developing Materials

The state, with input from the group above, has developed a number of materials for providers and consumers, although the consumer brochure is not required to be given to consumers. All materials are on the state's website.³²

- 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 the rationale for the changes to Section Q
 - Lists all roles and responsibilities
- Consumer Brochure (the state did not develop its own; it uses CMS's "Your Right to Information About Returning to the Community")
- Authorization to Use and Exchange Information
 - How to share information on a resident with all needed agencies, including Centers for Independent Living
 - It is designed for use by agencies that work together to jointly provide or coordinate services for individuals with complex needs.

Appointing a State Coordinator Specifically for Section Q

*"Many people can be transitioned; I am always trying to change that attitude."*³³

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 home staff, solves problems, takes family calls, etc. Her contact information is widely publicized.³⁴ She is trying to change the "old school" mentality of nursing homes that most residents cannot be transitioned.

³¹ Interview with Amy Burkett, BSW, State Section Q Coordinator, Program Analyst, Division of Long Term Care, Department of Medical Assistance Services, Maureen Hollowell, Endependence Center, Director of Advocacy and Services and the State Long Term Care Ombudsman, Joani Latimer, May/June, 2014.

³² See, http://www.dmas.virginia.gov/Content_pgs/ltc-fhbs.aspx

³³ Ibid.

³⁴ Interview with Amy Burkett, BSW, State Section Q Coordinator, Program Analyst, Division of Long Term Care, Department of Medical Assistance Services, May/June, 2014.

Monitoring

"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." (Cil Bullard)

All referrals are entered electronically into the state web portal. The State Section Q Coordinator receives quarterly reports of all referrals. 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.³⁵ She deals with them one-on-one as well as training (see below). 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 about Section Q and its importance.

The RAI (Resident Assessment Instrument) Coordinator has a concern that nursing homes have a tendency to make the decision for the residents; she tries to teach the person-centered care and the need to follow the RAI process.³⁶ She gave an example of a resident with cerebral palsy who was 30 years old. He had never been asked the Section Q question. The nursing home felt there were no services in the community and thus, did not ask him if he wanted to speak to someone about getting care in the community. Her message to nursing homes is that they cannot make the decision for the resident. They must follow the process. She feels that since there are no real consequences when a nursing home does not follow the process (it might lead to a low level citation), nursing homes do not make asking the question a priority.

The state is gathering data that will let it know what is actually going on; they have a system that can track everything. Using this data, they have made significant outreach to nursing homes with LCA community events. They are analyzing the data but have not found any strong trends; they have not yet figured out how to improve the process. State staff believe that education must be constant– referrals do go up when training is done. However, staff turnover leads to referrals going down. The state is continuing to glean data to decide how to continue the improvement.³⁷

Training

Virginia's RAI Coordinator trains nursing homes to make sure that they code Section Q correctly; she responds to facility questions. The training is very basic and is only 20 minutes of a larger training on MDS 3.0.³⁸ The training does quote CMS' rationale for the changes to Section Q. She trains new surveyors to look at Section Q as part of resident rights; surveyors will look at Section Q if they feel there is a need to.

The Local Contact Agencies and Centers for Independence have gone out to the nursing homes as well and trained them with the developed training materials. An advocate for the DD population stated that the Centers did outreach to the nursing home staff with mixed success. She felt that it depended on who is doing the presentation and how friendly the nursing home is.³⁹

³⁵ Ibid.

³⁶ Interview with Cil Bullard RN, CPC, Virginia RAI/OASIS Coordinator, Training Division, Office of Licensure and Certification, Virginia Department of Health, May/June, 2014.

³⁷ Interview with Katie M. Roeper, Department for Aging and Rehabilitative Services, State of Virginia, May/June, 2014.

³⁸ See, <http://www.vdh.state.va.us/OLC/training.htm>

³⁹ Interview with Maureen Hollowell, Endependence Center, Director of Advocacy & Services, May/June, 2014.

The State Section Q Coordinator has also trained the LCAs and the nursing homes.⁴⁰ The training gives the rationale for Section Q modifications:

- Gives resident a voice and a choice;
- Places resident/family at center of decisions;
- Increases person-centered care and discharge planning; and
- Increases communication and collaboration between providers of services.

The training clearly delineates the role of all participants: LCA, nursing homes, the Transition Coordination Providers (TCP) who may be contacted by the LCA with a referral, and Money Follows the Person.

There is also a refresher course for LCAs.⁴¹ All of this information is on the website⁴² (The State Section Coordinator also sends out "email blasts" to notify providers of any changes).⁴³

Participation of the Ombudsman Office

The State Ombudsman was involved in the original group developing the materials and the protocols. Local ombudsmen made contact with the nursing homes and discussed the changes. A new suggestion is for ombudsmen to seek out people who have returned to the home after being transitioned.⁴⁴

Developmentally Disabled

"It is not working – it is failing people with Developmental Disabilities – it is not providing the information." (Maureen Hollowell)

The triple As are the Local Contact Agencies. Advocates for the Developmentally Disabled believe that the LCAs for their population should be the Centers for Independence, not the AAAs. They believe that while some are knowledgeable about resources for the DD population, others are not. One advocate believes that the AAAs have a conflict of interest because they are Medicaid providers. She feels that the perception is that the AAAs are not providing choice of transition providers. According to her, the DD population does not know that they have options for a comprehensive DD waiver. "My organization has gotten significant numbers of DD and other people out of nursing homes, more than any other transition coordinators, yet we have gotten only **one** unsolicited referral in 4 years."⁴⁵ It is clear that the state is also concerned about this conflict of interest. In her training, the State Section Q coordinator gives this note: *NOTE: LCA's which are also TCPs (Transition Coordination Providers) should not promote their TCP services over other similar TCP organizations⁴⁶.

⁴⁰ See, [2013 MDS 3.0 Section Q Training for Local Contact Agencies & Nursing Facilities](#)

⁴¹ See, [2014 MDS 3.0 Section Q Refresher Training for Local Contact Agencies.](#)

⁴² See, http://www.dmas.virginia.gov/Content_pgs/ln-ltc.aspx).

⁴³ See, Appendix for example of an email blast.

⁴⁴ Interview with Joani Latimer, State Ombudsman, May/June, 2014.

⁴⁵ Ibid.

⁴⁶ See, [2013 MDS 3.0 Section Q Training for Local Contact Agencies & Nursing Facilities](#)

APPENDIX 1

State Case Studies

Virginia

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New Hampshire

Bringing Together All Stakeholders: Development of Implementation

The New Hampshire Department of Health and Human Services contracted with the University of New Hampshire's Institute for Health Policy and Practices to facilitate a project to build New Hampshire's capacity for the transition of residents referred from nursing facilities to community living. The very title emphasizes individual choice and control. The project is entitled: "Nursing Home *Person-Centered* Transition to Community Living Project." (Emphasis added)

In order to make sure that all stakeholders "bought in" to the project, the project coordinator from the University reached out to all the players. The University included nursing homes right from the start to make sure they were "on board." They were recruited to help both develop the process as well as build the curriculum for the statewide training. The Granite State Independent Living, which is a statewide nonprofit organization with seven offices around the state, was also an active participant in the planning process. According to the project director, it took a lot of time to make sure that everyone bought in. A large group of people representing various constituencies was formed. A small group formed from the larger group met twice a month for six months to create the referral process, the manual and the trainings. The process was then piloted to modify the process if necessary. They did learn from the pilot that they needed more communication. The process was given to the state for its approval and once approved, training began.⁴⁷

Developing Materials

Many materials were developed to focus on communicating the project to all stakeholders. The group developed brochures, letters, and intake package for new admissions. They developed a reference manual and special websites.

For Nursing Homes and LCAs: The Manual (MDS 3.0 Referral Toolkit)⁴⁸

The manual provides "a framework for facilitating person-centered planning with older adults and inspiring person-centered care practices in long term care facilities." It was designed to provide nursing facilities with the resources needed to assist residents who indicate an interest in returning to the community.

The manual includes the "Statement of Understanding between LCAs and Nursing Homes" and the Referral Notification form standardized for use by nursing homes for referrals, as well as other educational information. The Statement of Understanding provides a flowchart on how referrals are processed and includes roles and responsibilities of all involved. The Referral Notification Form serves as a tracking and documentation tool. The manual also includes the fact sheet for long term care ombudsmen developed by the National Long-Term Care Ombudsman Resource Center, and a clear description of the responsibilities of both the LCA and the nursing home in the referral process.

In addition, the manual includes tips for the nursing home social worker to help in discharge planning as well as how the role of the ombudsman is specifically related to transition. Tips included:

⁴⁷ Interview with Jean Crouch, MS., IHPP/Center on Aging and Community Living, UNH and Wendi Aultman ServiceLink Program Manager, NH Bureau of Elderly and Adult Services.

⁴⁸ See, <http://www.nh.gov/servicelink/documents/MDS3.0SectionQReferralReference-Resource.pdf>.

(1) "When a resident wants to *Return to the Community*, and the family members who would normally support the resident disagree, a difficult situation can arise. Calling the Office of the Long Term Care Ombudsman is helpful, as a Long Term Care Ombudsman can assist with problem solving, and will assist the resident by advocating for him or her;" and,

(2) "While you do have to use the language that the MDS 3.0 presents ("Do you want to talk to someone about the possibility of leaving this facility and returning to live and receive services in the community?"), you can create a conversation around question 0500, "*Return to the Community*". You can try asking the resident what his or her goals are for the upcoming year, where he or she sees herself in the next few months, what his or her ideal situation would be like, and ask questions about his or her community supports. This will help the resident to understand the question, and will create a more person-centered approach." The manual also includes a number of actual case studies for practice. For example:

Ms. K is an elderly woman who has been blind since birth. She lived with her parents growing up and then with her husband until he passed away. Terrified to live on her own, she moved into a nursing home about five years ago. She now uses a wheelchair 100% of the time. On her annual MDS assessment, Ms. K. responded "Yes" to item Q0500B Return to Community. She is an active and very social person and said that she desperately wanted to leave the facility to live on her own.

Ms. K's physician and the social worker at her nursing facility are very reluctant for her to leave the facility. They are very concerned about her safety while living alone, and for her being able to take care of her activities of daily living, because all of that was done for her in the facility.

1. Who has the right to make this decision?
2. Does Ms. K have the right to take the risk of moving out of the nursing facility?
3. If a competent individual resident determines that they want to talk to someone about returning to the community, does the nursing facility have the right to block the local contact agency from seeing the resident?

For Nursing Home Residents and Their Families: Return to the Community Brochure

Using the federal brochure, a brochure was modified for nursing home residents and their families. It delivers two messages to residents: (1) "You have the right to learn if you can live in the community and get the services and the support you need," and (2) "Learn more about your right to obtain information about returning to the community."

It clearly lists the mandate for nursing homes to ask the section Q question as well as what happens if the resident says, "yes".⁴⁹ It also lists the LCA, the Granite State Independent Living and the Long Term Care Ombudsman contact information. It was distributed to all nursing homes with suggestions for how to distribute to residents and family members such as: placing the brochure in the admissions packet and reviewing as with other documents, including it in the care plan meeting discussions, and during MDS 3.0 Section Q assessment times.

Coordinating

New Hampshire has a team of professionals that meet to help individuals transition to the community. The "team" includes the Choices for an 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. Money Follows the Person staff members participate if that resident wishes to utilize MFP services. The Office of the Long Term Care Ombudsman only becomes involved if the resident

⁴⁹ "Returning to the Community."

requests that it participate. In a number of circumstances these transitions occur without involvement by the ombudsman. The team meets as often as is necessary to develop a thorough, safe and appropriate discharge plan. Sometimes these matters may require a number of meetings over time as one after another of the potential barriers to the transition are overcome.⁵⁰

Granite State Independent Living as Contracted Resource to LCAs

ServiceLink, NH's statewide network of community-based connection for elders, adults with disabilities and their families serves as the Local Contact Agency for NH nursing facilities for Section Q referrals. ServiceLink staff provides community resource information for individuals interested in transitioning back to the community. The state has designated Granite State Independent Living (GSIL) as a resource to ServiceLink. GSIL is a statewide nonprofit organization whose mission is to promote life with independence for people with disabilities and those experiencing the natural process of aging through advocacy, information, education and support. If ServiceLink believes that the residents they are speaking to can benefit from some of GSIL's services, they ask GSIL to get involved. Staff from GSIL will then go to the nursing home to speak to the resident. They might also be part of the professional team discussed above.⁵¹

Training: Focus on Nursing Homes

On-Site

The University conducted statewide trainings on the Section Q referral process and person-centered approach. The trainings were designed to support nursing facilities with the implementation of the Section Q question. They offered participants continuing education credits.

Training sessions were lecture style, with visual illustrations and case study discussions. They were conducted throughout the State in a number of different settings, including nursing facilities and ServiceLink Aging and Disabilities Resource Centers. Each training session described the federal and state policy initiatives related to person-centered services and the implementation of Section Q. In addition, the training sessions presented an introduction to person-centered systems and approaches; provided instruction on the implementation of Section Q; described and illustrated the standardized referral process for individuals residing in nursing facilities who expressed the desire to learn more about their options to *Return to the Community*; described the role of the Long-Term Care Ombudsman in the Section Q process; and provided opportunities for discussion and questions. Participants at training sessions included staff (Administrators, MDS Coordinators, Discharge Planners, Social Workers) from nursing facilities, ServiceLink Aging & Disabilities Resource Center managers and long term support counselors, outreach staff from Granite State Independent Living, State Home & Community Based Care nurses, and the Bureau of Health Facilities Licensing personnel.⁵²

The state evaluated its training. According to the state evaluation,⁵³ the implementation of the MDS 3.0 Section Q was met with concern by nursing facility staff. Some of the nursing facility staff in the state have reported that this question triggered anxiety with certain residents and their support network (family and friends), and with nursing facility social workers who are responsible for the administration of Section Q. Nursing facility staff reported their frustration with the mandate of the Section Q referral requirement and felt that it is detrimental to the well-being of particular residents to be asked this question. Also, additional feedback from nursing facility staff has been that the mandate to include a local contact agency is perceived as though they are not fulfilling their responsibilities to their residents. These concerns were brought to light during the facilitated community process of developing the plan for

⁵⁰ Interview with Don Rabun, State Ombudsman, March, 2014.

⁵¹ Interview with Cheryl Pinheiro, RN, Certified Case Manager, GSIL.

⁵² Person-Centered Nursing Home Transition Into Community Project, Section Q Referral Process for New Hampshire.

⁵³ MDS 3.0 Section Q Training Evaluation Summary.

Section Q referrals discussed above. Some of the attendees came to the training with these concerns. The training tried to respond to these concerns.

The evaluation summary results indicate that the goals and objectives established for these trainings were successfully met. Both the trainers and training presentation received positive scores. Stakeholders (including nursing facility management and staff) had an active role in the development of 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 facility training requests and needs. Themes identified through the training process and exchanges with nursing facility staff included: person-centered strategies for providing person-centered supports to nursing home residents, increased training on the role of the Long-Term Care Ombudsman beyond Section Q, the role of the social worker in identifying individuals for potential community living, strategies for “asking the question” in difficult situations, responsibility of discharge/transition planning, and the key elements of transition/discharge planning.⁵⁴

Video

New Hampshire developed a 27 minute training module that can be streamed on line. It contains four chapters: MDS 3.0 Section Q The Tool; Local Contact Agency; The Referral Process; and Person-Centered Approaches.

Each chapter addresses specific aspects of the referral process. Resources for each chapter are listed on the website.⁵⁵ The last chapter discuss what a person-centered approach is, first discussing the case that led to the Olmstead Act and the Freedom Initiative signed by President Bush in 2001 - both promoting access to community care and life. The video goes on to talk about 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. The video is another way to help explain the process; it can be viewed at any pace and remains on line.

Dedicating a Position to Protect Resident Rights

The state has a dedicated person⁵⁶ whose main function is to focus on “person-centered care.” Under contract to the University of New Hampshire, she has a number of roles. She:

1. is a liaison between the Ombudsman Program and the Money Follows the Person Program; and
2. assists nursing home staff in “how to ask the Section Q question,” and encouraging resident rights to person-centered care.

Liaison

This individual transmits information back and forth between both programs. For example if MFP program is having a problem with a transition of a resident because the social worker believes the resident should stay in the facility, she is able to bring this issue to the Long-Term Care Ombudsman Program for their help. Since she is a certified ombudsman and the Ombudsman Programs’ intake

⁵⁴ Ibid.

⁵⁵ <http://www.nhsectionq.org/> video

⁵⁶ Interview with Kate Crary, Program Intake and Triage Coordinator/Ombudsman Liaison, NH Community Passport Program, UNH/IHPP in March, 2014.

coordinator she is perfectly placed to do this. She is also able to route certain cases to adult protective services and, with permission of the resident, to the board of nursing, state survey and certification etc.

Encouraging person-centered care

She travels across the state educating the nursing facilities the person-centered process as it relates to Section Q. She meets with Resident Councils (and the one Family Council in the state) to make sure they know what their rights are. She meets with social works in the facilities asking them if they have any issues with asking the question. She urges them to use a person-centered approach, giving specific suggestions in how to help residents understand the question and how to ask the question of people with intellectual disabilities. She urges the social workers to use the question to help improve the quality of life for those residents who may not be able to get care in the community by having a conversation with them about what their needs and desires are and what makes a home.

Monitoring the Process

Data analyst

As part of its contract with the University of New Hampshire, the state contracted with a data analyst. At this point, his role is to gather data from the MDS to see whether the number of “yeses” to the question related to referral are 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 meetings with the nursing homes have brought up a number of anecdotal issues to explain the inconsistencies with the numbers (why not all “yeses” are referred), such as some residents don’t understand the question, some residents get upset if they are asked, etc. In addition, the participants discussed ways to ask the question; that the words are confusing and that residents have to have trust the one asking the question. The UNH expects to use some of this information in developing state policy as it works with the state.

They hope 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.⁵⁷

They also recently met with the survey and certification division to discuss survey follow-up. They presented their data indicating that many residents ask to be referred but are not. Survey and Certification staff are looking at that data to see if it raises any red flags. At this point, they do not believe these numbers are indicative of any nursing home non-compliance and there is no special focus on Section Q and the referral question by surveyors.⁵⁸

Liaison with Long-Term Care Ombudsman Program

The liaison is kept apprised of the data collected by the Data Analyst. If she sees that a specific facility has a tough time or a discrepancy she, unofficially, tells the Ombudsman who goes to that facility to look into the discrepancy or problem. If the ombudsman finds the problem is systemic, s/he can tell the Survey and Certification division of the State Health Department.⁵⁹

⁵⁷ Interview with Abbott Williard, Project Director (Data Analyst), UNH, March, 2014.

⁵⁸ Interview with Lynne Deblois, Program Specialist.

⁵⁹ Interview with Kate Crary, Program Intake and Triage Coordinator/Ombudsman Liaison, NH Community Passport Program, UNH/IHPP in March, 2014.

Participation of the Ombudsman Office

The Office of the Long Term Care Ombudsman has always assisted residents who wish to return to the community. The Office was asked to provide commentary on a grant proposal for the Money Follows the Person (MFP) program in which a position for the office was included. The staff person became the intake worker for the Office while at the same time providing education to ombudsmen, nursing facility staff members, residents and family members of residents explaining the process to explore the possibility of returning to community living.

The State Long Term Care Ombudsman participated in the development of the implementation of Section Q and supported the education plan concerning Section Q 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 providers on Section Q.

The Office staff members and volunteers all received training on Section Q initially and thereafter received updated education when there were programmatic changes. The State Ombudsman believes the implementation has been a success because it has been successful in relocating residents to less restrictive environments and has also had the possibly unintended consequence of improving nursing home discharge planning.⁶⁰

Additional analysis

As stated above, the data analyst hopes 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. This is very important. This might raise red flags related to certain types of residents not being referred. The lack of referral might be appropriate but the state should investigate why this might be so. Are nursing home staff making the decisions rather than the resident; are certain types of residents being encouraged to say, "No?"

Involvement of the Survey and Certification Staff

It is important for the surveyors of nursing homes to monitor nursing homes compliance with this mandate. They should do random checks to see if the section Q question is being asked by both looking at the record and speaking with residents. Information gathered by the liaison between the MFP and the State Ombudsman Office should be part of the survey information.

⁶⁰ Interview with Don Rabun, State Ombudsman, March, 2014.

New Hampshire

MDS Section Q 3.0: A Fact Sheet for Residents

- The MDS 3.0 Section Q is to identify if you would like to learn about your options for returning to the community
- If you say "yes", someone from ServiceLink Resource Center will come and meet with you to talk about your options
- If you say "yes", it does not mean that you have to leave the facility.
- If you have a guardian or power of attorney, you still have a right to be asked questions concerning your preference to learn about services.
- Sometimes, returning to home is not possible. This is something that you and your care team should discuss.
- If you find that being asked these questions is harmful or upsetting to you, you can decide to be asked these questions less often.
- The facility you live in is responsible for discharge planning, and for including you in the planning process.

Questions? We would love to help!

Contact:

**The Office of the Long Term Care Ombudsman
129 Pleasant Street
Concord, NH 03301
603-271-4375 Or 1-800-442-5640**

Facility Poster:

MDS 3.0 Section Q and You:

Your Right to Learn About Community Living Options

Please join us at _____, on _____, for an informational session on the new MDS 3.0 Section Q. Learn about your right to know about community living options, how you can take advantage of the new referral process, and more!

Kate Crary, from the Office of the Long Term Care Ombudsman, will be on hand to talk with you about the topics listed above, and to answer any questions you may have.

Please contact

If you have any questions, or if you would like to reserve a spot.

**Office of the Long Term Care Ombudsman
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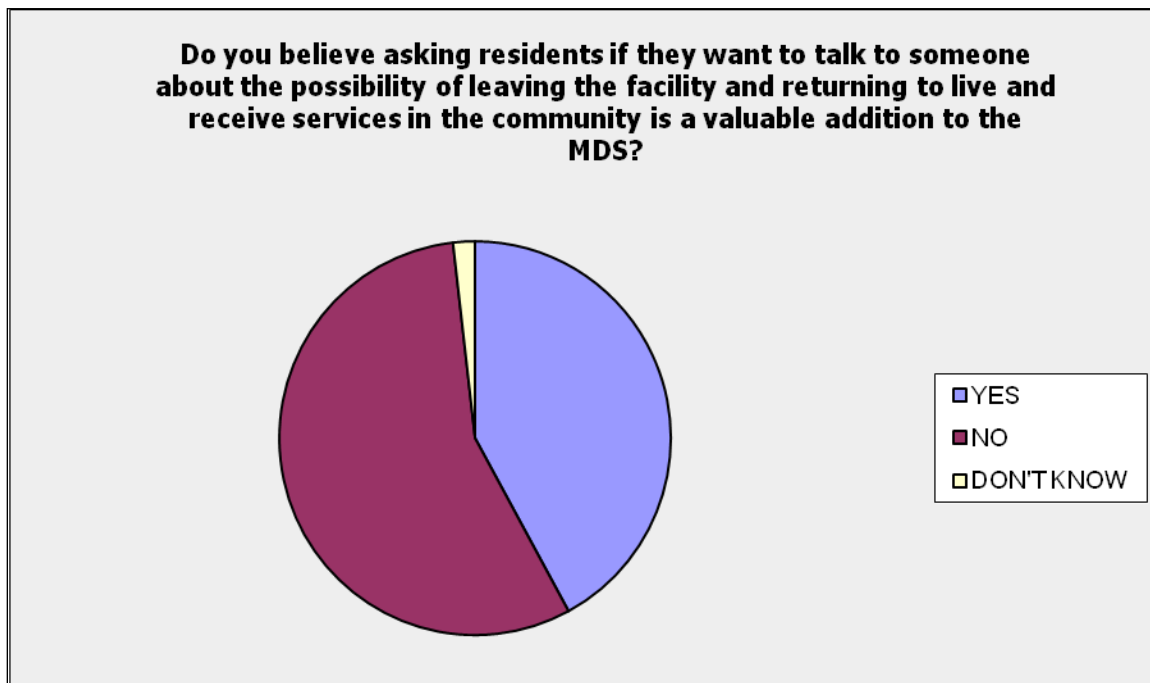
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APPENDIX 2 – Survey Summary from Section Q - Providers

Question 1:

| Do you believe asking residents if they want to talk to someone about the possibility of leaving the facility and returning to live and receive services in the community is a valuable addition to the MDS? | | |
|--|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| YES | 42.1% | 24 |
| NO | 56.1% | 32 |
| DON'T KNOW | 1.8% | 1 |
| <i>answered question</i> | | 57 |
| <i>skipped question</i> | | 2 |



APPENDIX 2 – Survey Summary from Section Q - Providers

Question 2:

| Please tell us why you believe it is valuable. Please check ALL that apply. | | |
|--|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| It has helped me save time by having another entity discuss community options. | 27.3% | 6 |
| The local contact agency (LCA) has helped me find resources for discharge. | 9.1% | 2 |
| A number of residents who may not have been discharged have been. | 13.6% | 3 |
| I have had the opportunity to really find out what my residents want by asking the question. | 68.2% | 15 |
| None of these | 22.7% | 5 |
| Other? | | 3 |
| <i>answered question</i> | | 22 |
| <i>skipped question</i> | | 37 |

Comments

It empowers the resident; knowing that they have other options in the community.

We should have the option not to ask the question if we have a resident that is too compromised they do need to stay in the nursing home or the family and resident do not wish to leave. We need a box to check off better than just asking one every quarter

It is important to periodically ask the resident what they expect as long as he or she has decision making capacity. If not, than it is also valuable to check in with the Designated Representative to make sure we understand what the goal is in terms of long term or short term placement.

APPENDIX 2 – Survey Summary from Section Q - Providers

Question 3:

| Please tell us why you think it is not valuable. Please check ALL that apply. | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| I do not have the time I need to ask this question in a meaningful way. | 9.7% | 3 |
| I am not comfortable asking this question. | 0.0% | 0 |
| I have been doing this for years; I do not need another entity to give information to the residents. | 16.1% | 5 |
| Residents are confused and upset when I ask the question. They think I am asking them to leave. | 71.0% | 22 |
| Residents who are referred are upset when things go slowly and they are not discharged quickly after being referred. | 58.1% | 18 |
| Most residents to whom I ask the question could never get discharged anyway; it's a waste of time and it raises false hope. | 80.6% | 25 |
| There are no resources in the community for most of our residents. | 45.2% | 14 |
| Most residents need the level of care provided in our nursing home - they can't get that anywhere else. | 58.1% | 18 |
| Some residents with cognitive or intellectual disabilities don't understand the question. | 74.2% | 23 |
| It has been hard to deal with families/significant others of residents who are cognitively impaired or intellectually disabled. | 19.4% | 6 |
| Some family members are angry that I am asking the question; they tell me that the resident has to stay in the facility. | 48.4% | 15 |
| My job is to make sure that residents get the best care in the nursing home, not to send them back to the community. | 3.2% | 1 |
| None of these | 6.5% | 2 |
| Please Explain | | 12 |
| <i>answered question</i> | | 31 |
| <i>skipped question</i> | | 28 |

Comments

Once asked, people for whom discharge is unrealistic persevere on the possibility creating disappointment when it doesn't work out.

Often times, if not at all times, the resident is alert and able to speak, but is confused and often disoriented, but is able to remember home and usually often able to state "I want to go home or talk to someone about going home" but this resident is unable to understand the nature of their illness and/ or financial constraints and/or the nature of all supportive services required to remain in community.

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Therefore, we are doing them an injustice of raising false hopes where a discharge to community may never occur.

I feel that if discharge is possible a good social worker will initiate planning and do not need to wait for the MDS question. Due to lack of affordable housing in my area not one individual referred to the agency has been discharge to the community

Residents answer "yes" to the question however; they are not proper candidates to receive community based services. Their needs exceed what the CBO's can provide.

Local contact agency is not helpful.

We evaluate resident potential for referral to community and refer when appropriate. Asking the question of residents with no potential or confused residents causes unnecessary anxiety.

These questions are not well understood by residents and/or family.

My experiences have been more negative in regards to this. Often residents are asked this and they truly do warrant a SWF and due to not a lot of resources in the way of family or housing/support it is unrealistic, other times residents who have been here a good number of years fear that they are being asked to leave. Most of all residents who do have the desire to be discharged ask or the families do - social workers also are able to utilize their own skills to determine with the help of (unreadable) who can be discharged appropriately.

may be appropriate for those res. who are short-term, but it is not really necessary for a LT resident- if they want to consider d/c (to community or another facility) they or their family will certainly ask,...

It takes a long time after requesting for someone to come to meet with a resident to finally come and then months to get anything in writing that they were here.

Often times there are not reliable resources for the resident in the community or ongoing funding is not available for some of the needed services for a safe discharge plan

Many of our residents are in their 40's and 50's and are homeless, often with no benefits. They are limited places for these people to go, so when a rep comes to discuss housing options, there aren't too many places that would be appropriate. Additionally, most of these residents are not mentally ill and would not be accepted to some of the places suggested. Other residents are very demented and often want to "go home." So, the question seems pointless to ask, especially if the resident has no understanding of the safety concerns. Most of these residents need 24 hr. care which is difficult to get. The nursing home transition waiver program that is often suggested, takes over a year and it's been hard for agencies to locate apartments. Every apt. that is located is often in the Far Rockaway area, where most people are not interested in living. I could go on and on about various experiences I've had, but it would be too lengthy.

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Question 4:

| If you said, "I am not comfortable asking the question," what can be done to make you more comfortable? Check ALL that apply. | | |
|--|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Getting specific training on how to ask this question. | 0.0% | 0 |
| Discussing this with colleagues and supervisors. | 0.0% | 0 |
| Does not apply. | 100.0% | 21 |
| Other (please specify) | | 0 |
| <i>answered question</i> | | 21 |
| <i>skipped question</i> | | 38 |

Question 5:

| If you said, "Some residents get upset; they think they have to leave," how might you solve this issue: Please check ALL that apply. | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Make sure the resident fully understands why you are asking this question; it is being asked to see if they want to pursue discharge; they do not have to if they do not want to. | 37.0% | 10 |
| Not ask the question to residents who have been in the facility for a long time. | 22.2% | 6 |
| Talk to family members or guardians and get them to help explain why you are asking the question. | 22.2% | 6 |
| Residents and family members need to be educated about this process before we ask the question. | 44.4% | 12 |
| Does not apply. | 22.2% | 6 |
| Other. | 11.1% | 3 |
| Please explain | | 6 |
| <i>answered question</i> | | 27 |
| <i>skipped question</i> | | 32 |

Comments

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

If a resident is long term and either very heavy care or confused, why ask the question since all home care agencies require a back up for 24 hours care or will not provide enough care for confused residents. Why ask residents who are comfortable in the facility and upset them? Believe me that residents who want to be discharged ask for it.

Residents and families may not fully understand these questions and the whole MDS process in general. Educating them possibly might help make asking the questions less problematic. Even after explanation of why the question is asked and that supportive services could be facilitated it does cause anxiety in some residents due to feeling fears and insecurity.

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Residents have the right to refuse medication and treatment but do not have the "right" to not be asked about discharge, even on a "full" assessment? This is nonsense

None of the above would be helpful. Even cognitively intact people who are asked the question think it's a ridiculous question to ask when they've been living in a place for over 5 years.

Question 6:

| If you said, "Some residents with cognitive impairment or intellectual disabilities don't understand the question," how do you think we could solve this issue: Please check ALL that apply. | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Don't ask the question to residents with cognitive impairment or intellectual disabilities and document why. | 53.8% | 14 |
| Get guidance on how to better ask the question with this population. | 7.7% | 2 |
| Talk to family members or guardians first. | 34.6% | 9 |
| Does not apply. | 30.8% | 8 |
| Please explain | | 4 |
| <i>answered question</i> | | 26 |
| <i>skipped question</i> | | 33 |

Comments

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

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.

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.

If resident has do of ID or cog impairment can skip question, no need to doc further.

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Question 7:

| If you said, "It has been hard to deal with families/significant others of residents who are cognitively impaired or intellectually disabled," how would you solve this issue: Please check ALL that apply. | | |
|--|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Get better guidance on how to deal with families/guardians. | 4.3% | 1 |
| Ask the family to choose one individual to be involved. | 8.7% | 2 |
| Families/guardians do not need to be involved. | 0.0% | 0 |
| Residents and family members need to be educated about this process before we ask the question. | 26.1% | 6 |
| Does not apply. | 69.6% | 16 |
| Other. | 4.3% | 1 |
| Please give details | | 2 |
| <i>answered question</i> | | 23 |
| <i>skipped question</i> | | 36 |

Comments

Mostly we admit short term residents and then the problem comes when we feel the res has achieved max potential in rehab and then the family is not supportive of d/c.

Some families unfortunately just do not want to be involved. They know that their family member is in a safe place and can rest now at night. Often they become aggravated when I attempt to ask this question as they do not want them to leave.

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Question 8:

| If you said, "Some family members are angry that I am asking the question; they tell me that the resident has to stay in the facility," how would you solve this issue? Please check ALL that apply. | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Don't ask the question if the family objects. | 14.3% | 4 |
| Take time to explain the reason the question is important. | 28.6% | 8 |
| Get guidance on how to deal with the family. | 7.1% | 2 |
| Residents and family members need to be educated about this process before we ask the question. | 39.3% | 11 |
| Does not apply. | 39.3% | 11 |
| Other. | 3.6% | 1 |
| PLEASE EXPLAIN | | 7 |
| <i>answered question</i> | | 28 |
| <i>skipped question</i> | | 31 |

Comments

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 to family member because resident may require more care than family and home care can provide.

Many family members I interact with have a very difficult time coming to terms with long term placement and do so after other options have been explored bringing the issue up again is very upset to many who have come to terms with no placement being appropriate at this time, I believe the question only gets families more frustrated and confused especially those who have had a long road coming to terms with this decision and then are wondering why we are bringing it up again.

I have taken time to explain before, they still get upset.

I have res who want to go home but his daughter cannot and will not take him home she is very upset that we ask this question she knows we have to but she will not take him home with any amount of homecare.

This occurs on some occasions especially for adult children of residents who work or spouses who are becoming more fragile themselves.

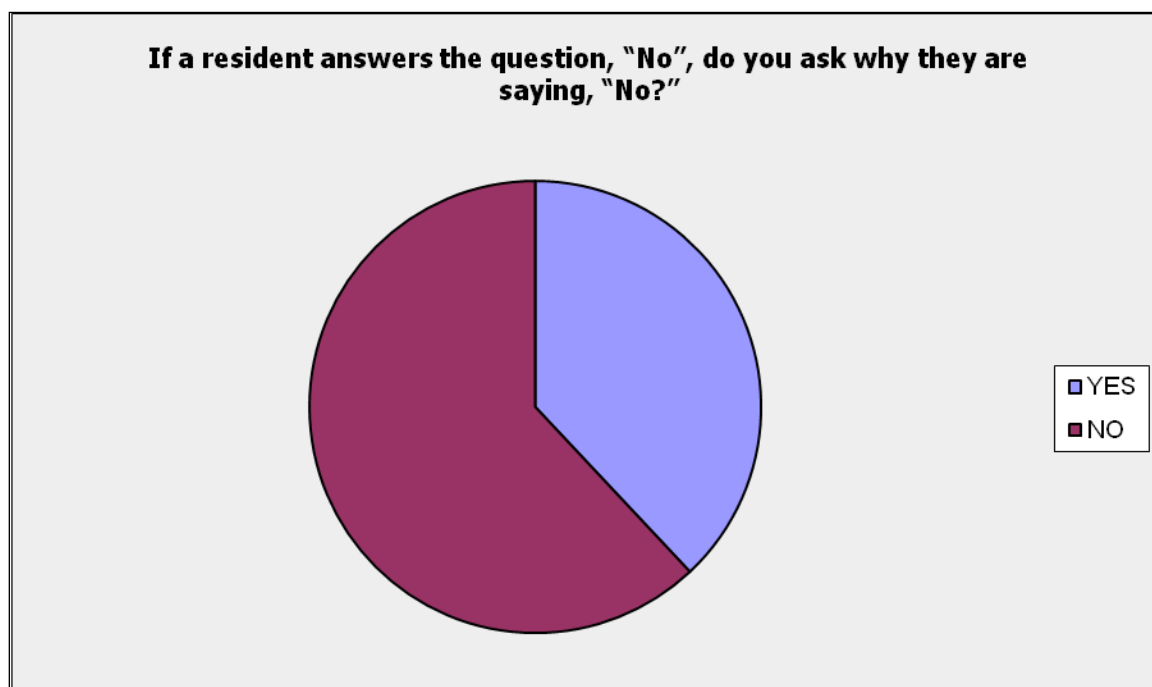
Document that this is the case.

I've been told by families, that they think the question is ridiculous to ask each and every time.

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Question 9:

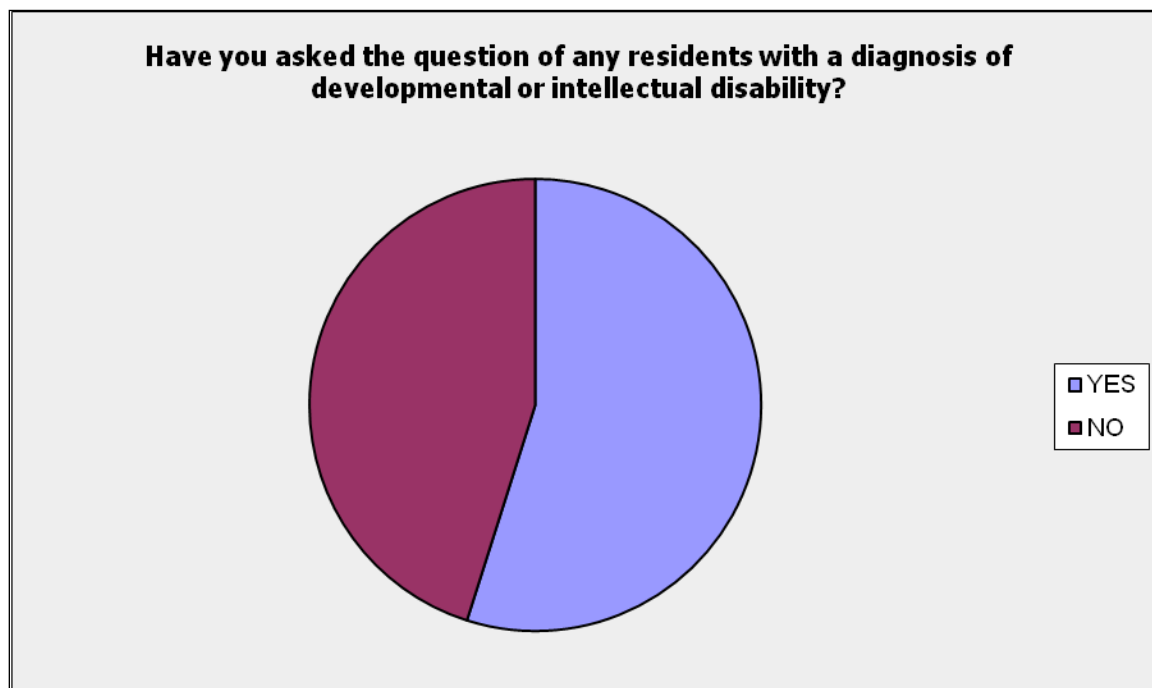
| If a resident answers the question, "No", do you ask why they are saying, "No?" | | |
|---|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| YES | 38.0% | 19 |
| NO | 62.0% | 31 |
| <i>answered question</i> | | 50 |
| <i>skipped question</i> | | 9 |



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Question 10:

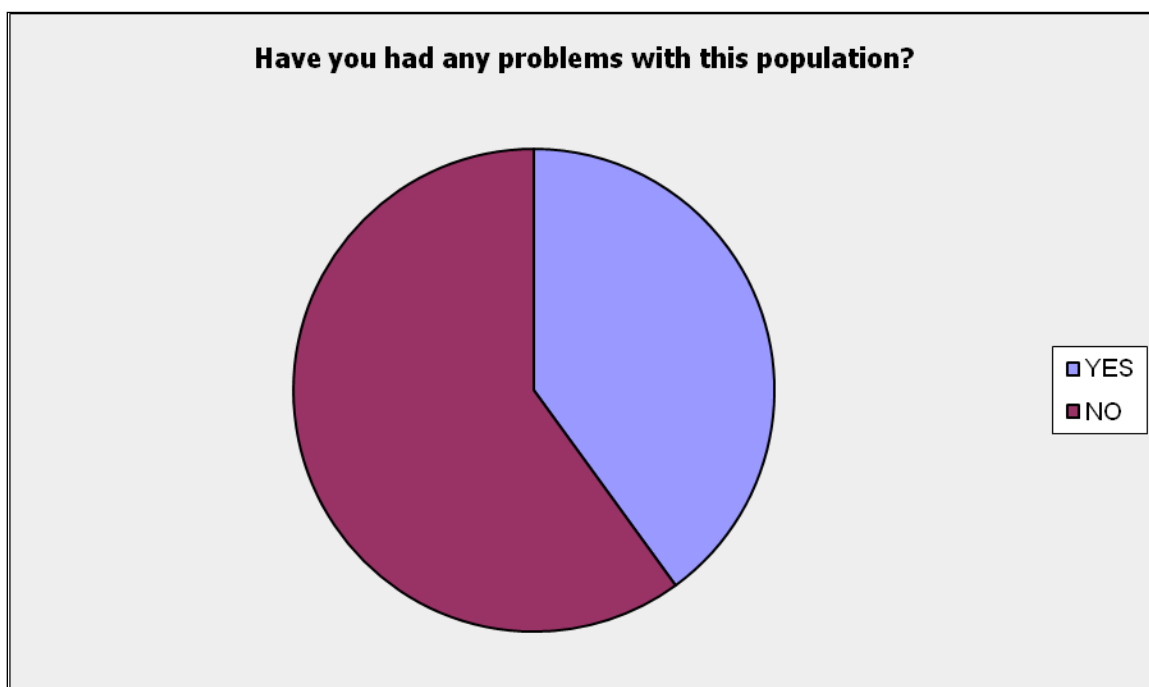
| Have you asked the question of any residents with a diagnosis of developmental or intellectual disability? | | |
|--|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| YES | 54.9% | 28 |
| NO | 45.1% | 23 |
| <i>answered question</i> | | 51 |
| <i>skipped question</i> | | 8 |



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Question 11:

| Have you had any problems with this population? | | |
|---|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| YES | 40.0% | 12 |
| NO | 60.0% | 18 |
| <i>answered question</i> | | 30 |
| <i>skipped question</i> | | 29 |



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Question 12:

| What types of problems have you had? Please check ALL that apply. | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Residents with intellectual or developmental disabilities are not able to understand the question or say they don't know. | 54.5% | 6 |
| Family members/guardians of residents with developmental disabilities can be hard to deal with. | 45.5% | 5 |
| Residents are difficult to deal with when they have different goals from guardians/family members. | 72.7% | 8 |
| I don't know about resources for people with developmental disabilities. | 18.2% | 2 |
| I don't know who in the community to contact for people with developmental disabilities. | 27.3% | 3 |
| Other. | 18.2% | 2 |
| Please give details | | 4 |
| <i>answered question</i> | | 11 |
| <i>skipped question</i> | | 48 |

Comments

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

The resources for housing are so limited, it takes months to even get someone from NY State 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 to community.

Speaking with this population requires simplicity in explanation for processing and has lead to increased anxiety regarding what will happen to them.

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Question 13:

| If you said, "Residents with Intellectual disabilities are not able to understand the question or say they don't know," how can you solve this issue: Please check ALL that apply. | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Don't ask them and document why. | 0.0% | 0 |
| Get guidance on how to approach residents with developmental disabilities. | 44.4% | 4 |
| Explain by simple language and simple sentences. | 77.8% | 7 |
| Try to find out if they have fears of leaving the community that can be dealt with. | 66.7% | 6 |
| Does not apply. | 22.2% | 2 |
| Please add details | | 0 |
| <i>answered question</i> | | 9 |
| <i>skipped question</i> | | 50 |

Question 14:

| If you said, "Family members/guardians of residents with developmental disabilities are hard to deal with," how would you solve this issue? Please check ALL that apply. | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Get guidance on how to deal with guardians and family members. | 20.0% | 2 |
| Refer guardians and family members to the local contact agency. | 40.0% | 4 |
| Make it clear that guardians/family members should discuss their issues with you directly. | 30.0% | 3 |
| Allow time for discussions with you, guardians/family members and the resident. | 40.0% | 4 |
| Does not apply. | 60.0% | 6 |
| Other (please specify) | | 0 |
| <i>answered question</i> | | 10 |
| <i>skipped question</i> | | 49 |

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Question 15:

| If you said, "Residents are difficult to deal with when they have different goals from guardians/family members," how might you solve this issue? Check ALL that apply. | | |
|--|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Get specific training on how to deal with this issue. | 66.7% | 6 |
| Get support from supervisors. | 66.7% | 6 |
| Does not apply. | 11.1% | 1 |
| <i>answered question</i> | | 9 |
| <i>skipped question</i> | | 50 |

Question 16:

| If you said, "I don't know about resources for people with developmental disabilities, or who in the community to contact for people with developmental disabilities," what could be done to help you? Check ALL that apply. | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Ask the LCAs to come in to give a presentation of resources and contacts. | 55.6% | 5 |
| Ask local independent living center to come in to give a presentation of resources. | 33.3% | 3 |
| Does not apply. | 44.4% | 4 |
| Other. | 0.0% | 0 |
| Other (please specify) | | 0 |
| <i>answered question</i> | | 9 |
| <i>skipped question</i> | | 50 |

APPENDIX 2 – Survey Summary from Section Q - Providers

Question 17:

| If you have not had any problems, what do you think is the best way to interact with residents who have developmental or intellectual disabilities when asking this question? | |
|--|-----------------------|
| Answer Options | Response Count |
| | 12 |
| <i>answered question</i> | 12 |
| <i>skipped question</i> | 47 |

Comments

N/A

Asking some residents with developmental or intellectual disabilities such question gives them false hope. By asking such question some think they are going to be discharge to the community immediately. We ought to be mindful on how we present such question to these residents.

Keep the conversation simple and to their level of understanding. Make sure they are in a safe place and in an office with little to no interruptions.

Be reassuring to the resident.

Each person with a developmental or intellectual disability is different and my approach is different depending on their level of understanding.

Directly ask but also involve the Designated Representative as indicated.

We have not had significant problems with this population.

N/A

To have a family member who is actively involved be involved in conversation.

Pose it in another way, not such a leading question that they may misunderstand

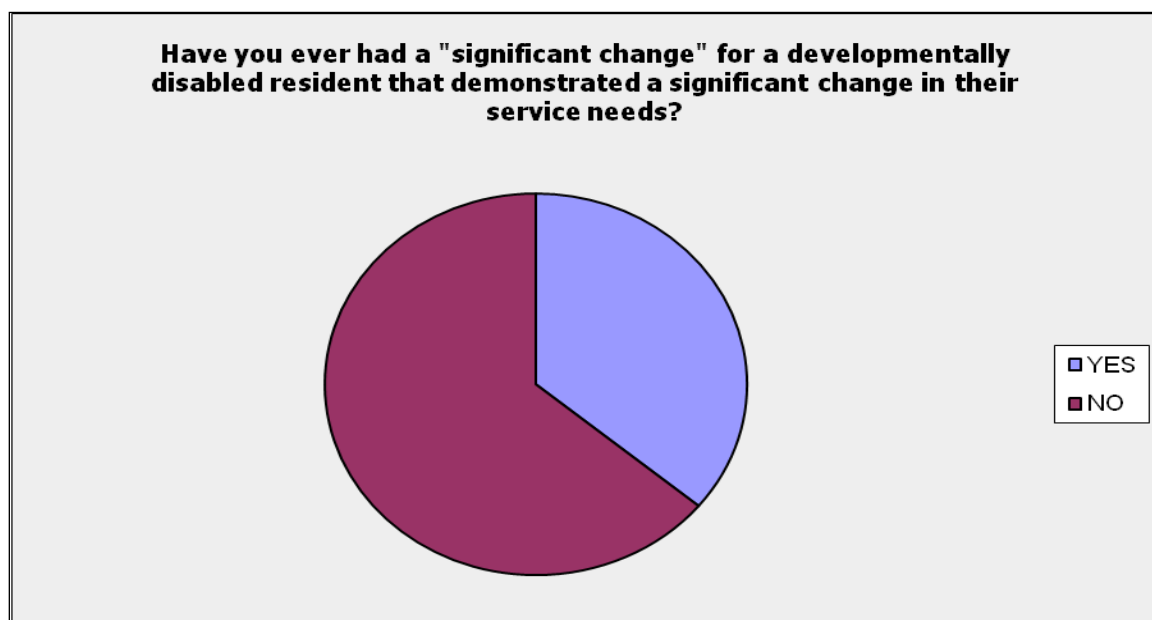
Speak with their authorized representative

We do not service a great number of residents in this category. Most have a place to return to and are accepted back willingly. It is more an opportunity to understand the resident's feelings about the subject.

APPENDIX 2 – Survey Summary from Section Q - Providers

Question 18:

| Have you ever had a "significant change" for a developmentally disabled resident that demonstrated a significant change in their service needs? | | |
|---|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| YES | 36.0% | 9 |
| NO | 64.0% | 16 |
| <i>answered question</i> | | 25 |
| <i>skipped question</i> | | 34 |



APPENDIX 2 – Survey Summary from Section Q - Providers

Question 19:

| If yes, who did you notify? Check ALL that apply. | | |
|---|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| Supervisor | 57.1% | 4 |
| Local Developmentally Disabled Agency | 85.7% | 6 |
| No one | 0.0% | 0 |
| Other | 14.3% | 1 |
| Please tell us who you notified | | 3 |
| <i>answered question</i> | | 7 |
| <i>skipped question</i> | | 52 |

Comments

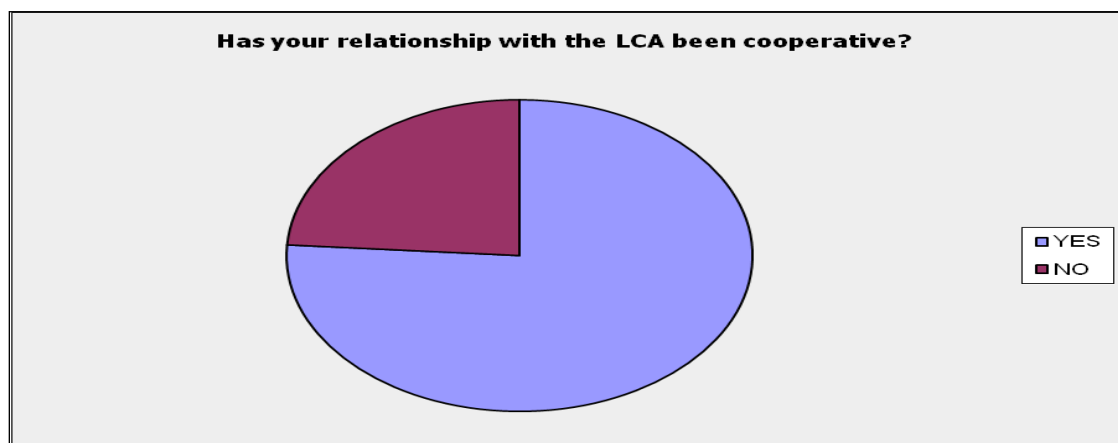
Individual was not DD

The case manger involved with the person

Next of Kin

Question 20:

| Has your relationship with the LCA been cooperative? | | |
|--|------------------|----------------|
| Answer Options | Response Percent | Response Count |
| YES | 76.1% | 35 |
| NO | 23.9% | 11 |
| <i>answered question</i> | | 46 |
| <i>skipped question</i> | | 13 |



APPENDIX 2 – Survey Summary from Section Q - Providers

Question 21:

| If your relationship with the LCA has been cooperative, what has worked well? | | |
|--|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| The LCA keeps in touch with me as s/he works with my resident. | 47.1% | 16 |
| The LCA helps me find resources in the community. | 35.3% | 12 |
| Other - see below | 32.4% | 11 |
| Please add details | | 12 |
| <i>answered question</i> | | 34 |
| <i>skipped question</i> | | 25 |

Comments

The LCA is easily accessible to answer any questions I have.

They normal provide us with information about their programs but we have not been successful in placing anyone yet.

The LCA has been cordial but provided resources that for the most part I have already plumbed.

LCA does not have much of a presence - virtually no help.

Basically I was referred to the nursing home transitions and waiver program which is comprehensive but very time consuming and takes ages and really puts a lot of the planning on the social worker in the nursing home and they have not been clear about delineation of responsibilities. It takes hours to find an agency that wants to take a new case. Some of the agencies are not responsible and do not get back to you. Some are not taking new cases, i.e. one is only taking TBI at present.

The LCA is cooperative but housing is often not forthcoming

They have communicated well with us for general information.

The interaction was cooperative, but the outcome useless. The LCA provides information only; in my experience no follow-up or assistance in locating community resources is offered. It would be just as helpful to conduct an independent online search for resources or use personal networking contacts.

LCA presently not working with any but when we have it takes forever to make appointments, months it, they rarely call back I make numerous phone calls. Very bad system

The LCA is responsive, but our area lacks the resources (not enough housing and home care) for them to do more than "counsel" the resident.

No one has wanted to leave when staff from "money follows the resident" comes

They are pleasant and visit fairly quickly, but never have anything that could be of use to our residents.

APPENDIX 2 – Survey Summary from Section Q - Providers

Question 22:

| If your relationship with the LCA has not been cooperative, what has not gone well? | | |
|--|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| I don't know really know what the LCA does. | 41.7% | 5 |
| I don't know what happens once my resident is referred and my resident comes to me to find out what is going on. | 41.7% | 5 |
| The LCA does not keep in touch with me once s/he meets with my resident. | 16.7% | 2 |
| I don't need the LCA – it's a waste of time. | 25.0% | 3 |
| Other, see below | 25.0% | 3 |
| Please add details | | 6 |
| <i>answered question</i> | | 12 |
| <i>skipped question</i> | | 47 |

Comments

3 of 4 of the people identified did not pass the interview; the 4th has a legal guardian that's non-cooperative and getting ready to have survey

They take too long is processing the paperwork.

The residents who reside in this facility are all HASA eligible and receive services when ready for placement.

I do not know where to send referral for LCA to. They have not been involved in my cases.

I do not work with residents who are here for short stay & looking for d/c assistance.

We have only used it twice and both times they were unable to assist us/ the resident.

Question 23:

| Has the ombudsman been involved in this process? | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| YES | 20.4% | 10 |
| NO | 79.6% | 39 |
| <i>answered question</i> | | 49 |
| <i>skipped question</i> | | 10 |

APPENDIX 2 – Survey Summary from Section Q - Providers

Question 24:

| If the ombudsperson has been involved, what has s/he done so far? | | |
|--|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| Investigated and resolved resident complaints related to the transition referral or process, | 77.8% | 7 |
| Supported residents in their decision-making related to transitions. | 44.4% | 4 |
| Provided information to consumers and providers (i.e. consultation to individuals) and facility staff (i.e. consultation to facilities) about resident rights and options. | 33.3% | 3 |
| Helped to identify candidates for transitioning to community living and making referrals as appropriate. | 11.1% | 1 |
| Other (please specify) | | 2 |
| <i>answered question</i> | | 9 |
| <i>skipped question</i> | | 50 |

Comments

Ombudsmen do not have information on community resources

I am not aware of the actions of the ombudsperson

Question 25:

| Soon all your residents who are covered by Medicaid will have to join a managed long term care plan. Do you think this will affect this process? | | |
|---|-------------------------|-----------------------|
| Answer Options | Response Percent | Response Count |
| YES | 38.0% | 19 |
| NO | 10.0% | 5 |
| Don't Know | 52.0% | 26 |
| <i>answered question</i> | | 50 |
| <i>skipped question</i> | | 9 |

APPENDIX 2 – Survey Summary from Section Q - Providers

Question 26:

| How do you think adding those who are covered by Medicaid will affect this process? | |
|--|-----------------------|
| Answer Options | Response Count |
| | 15 |
| <i>answered question</i> | 15 |
| <i>skipped question</i> | 44 |

Comments

MLTCs will want more people discharged to alternate settings, but where?

More involvement and more time needed for each resident.

Now that managed care is involved we must involve them and this may delay the process.

It will be harder to provide services for the patients.

The plans have to be picked out carefully. Many manager care companies do not have coverage in our area. Plus it has to be a good match the RX plans that the resident has. Going to be very difficult to cont. the level of medical services need for these residents.

MLTC will provide cuts on services needed by the residents when discharged to community.

It will limit and or change their current providers in the community. Residents will have to enter into a plan and choose providers within the plan network. Their current providers may not be in the plan network.

I don't understand why the resident cannot be assessed while in the nursing home by an MLTC. If you send a res home without an MLTC all the CHHA's and LHCSA's give a maximum of 8 hours of care and then the family has to put their lives on hold and then when the resident goes home they get to choose an MLTC and sign up by the 20th of the month and then pray and hope that they are approved for the amount of care they need to be safe in the community and the MLTC can only start the first of the following month. How can you plan a safe d/c that way??????

An Insurance Plan Case Manager will be involved.

The MCO will add another layer of involvement.

It will make the financial aspect of helping our residents even more of an issue.

I think it may limit discharge options.

More folks to d/c.

Limited resources.

Most MLTC's want to keep their participants in their plan however they do not want to provide the hours of service needed.

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Question 27:

| Please feel free to add any additional information. | |
|---|----------------|
| Answer Options | Response Count |
| | 5 |
| <i>answered question</i> | 5 |
| <i>skipped question</i> | 54 |

Comments

Two residents have requested a return to the community only to be informed that they were not eligible. In both cases the experience had a negative emotional impact.

For me, the entire MDS 3.0 process is the proverbial "exercise in futility." I do it because I must as part of my job, but I attach little relevance to any of the information I get. The only section that I find marginally helpful is Section C, which purports to assess cognitive status. In my opinion, the MDS 3.0 is a tool to drive reimbursement only...it is not at all a valuable assessment of an individual's status and capabilities. And it certainly does not respect individual preferences...just the opposite. The standardized, "cookie-cutter," questions are embarrassing, insulting, and demeaning. I regret that caring for people is driven by bottom-line monetary concerns and that the ever-increasing need for such documentation leaves us ever-decreasing time to develop meaningful relationships with our resident-clients.

However Medicaid case managers should be required to assist with providing options to residents.

For a SW who has been doing this for over 15 years and based on the comments I have heard from other SW's, the question is strange, not effective and tedious. On the most part, if someone has the ability to leave the nursing home to go to a community setting, we pursue it and place them in the most appropriate place. Those residents that are alert and want to leave speak up for they without my having to even ask. This goes for the families as well who would like to see their loved one in a community setting. If it's possible, then we do it. But to offer information of no use or to offer information that takes years to obtain, like the Medicaid waiver NH transition program, it's simply a waste of time. It gets them excited and hopeful and is not often appropriate.

There is a large number of resident who fall between the cracks of needing skilled care versus 24 hour supervision. They are not reimbursed for the type of supervision they need and they don't qualify for care at home.

APPENDIX 3: Advocates and Former Nursing Home Residents

Advocate Interviews:

We spoke with advocates throughout the state who have been working with people with developmental disabilities and with nursing home staff. Their experiences have been with people with developmental disabilities in all types of institutional settings and with helping people transition back to their communities.

What do you think needs to happen to make transition easier for people with developmental disabilities who are in nursing homes?

"Education of nursing home staff on what kind of services and supports are available. How they can get services in the community so that someone move out of the nursing home."

"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."

"I would love to see more training about developmental disabilities. A lot of people with developmental disabilities who are capable with diverse skill sets."

"There needs to be more training of nursing home staff regularly to support people to have a meaningful life. 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. Nursing home staff have to be helped to understand how this process works. In Long Island, their perception was that people could not get services in the community. Staff couldn't conceive of community living for people with developmental disabilities."

"Families are also 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."

What communication issues have been barriers for people with developmental disabilities in nursing homes?

"Sometimes people with developmental disabilities who have been in a particular situation with certain kinds of services will say, "I have to have this," because that's all they know. You have to be prepared to help them understand other options. Also bad experiences can color what's going on. If someone is treated badly when they ask questions or ask for some kind of service, they tend not to ask again."

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People assume that those with developmental and cognitive disabilities can't learn or change, that they are stuck in the situation, that's not true."

"People's behavior can help tell the story – a person might not be straight forward advocating for themselves, but they're crying every day – (it means) they're not happy. They're telling you something."

"There is often a disconnect. Some Medicaid service coordinators who have been supporting and working with someone with a developmental disability drop the ball when the person is in the nursing home. One gentleman I know in a nursing home takes paratransit to go to places and does things outside the nursing home because he can. He ended up in the nursing home because he couldn't afford his home any longer. It's interesting. Had the connection not been dropped with Medicaid service coordinator he might have found other options."

"People who have the ability to be in the community sometimes are not willing to try to leave now because of fear, things went awry and they are afraid they will again."

"Nursing homes are all about medical care. Our program is more about people living in the community. The connection between OPWDD and nursing homes is broken. They are not following a person who enters nursing home."

How would you change how Section Q is asked?

"We talk about choices, basic choices in everyday life and how you can build on those – start the conversation there. 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, 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?"

Section Q can't be asked just alone. People with developmental disabilities could be making many choices in their life and the Section Q question should be made in context: what else could they be choosing?"

"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."

"Nursing home staff see Section Q as just a paper issue. Fill out the forms. They are not doing it, asking the question in person. People are not making visits. They do it by paper work. And, the answer is predetermined by paperwork done by Social Worker. There's a disconnect because they don't see or talk to people."

"There are people who do have very profound disabilities – you can't ask them. They may not be able to tell you what they want. It's very hard to tell what they want even when you use different tactics. There are, however, other ways to look at those folks. We didn't even get the opportunity in nursing homes to talk to people like that – they didn't even introduce them to those people."

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"The biggest thing is to simplify the question and the explanation and make sure that people are doing their visits. The simple act of going to talk to somebody face to face makes a difference. Make sure people are following them when they go into the nursing home – checking in making sure things are happening. We should not leave them in the nursing home when they can live in the community."

Former Nursing Home Residents with disabilities now living in the community:

Three individuals who had been in a nursing home and were now in a group home were interviewed. One individual has mild developmental disabilities, depression and anxiety. The second has moderate developmental disabilities and schizophrenia, and the third has developmental disabilities along with medical problems.

Nursing Home Experience

All three disliked their time in the nursing home and wanted to receive care in the community. One individual used the word, "nasty." The place was "nasty;" people were treated, "nasty." "When you would call, they wouldn't come." Another did not like the loudspeakers or the food. One felt that the staff were not kind. Another interviewee felt that he was treated pretty well, but likes it better living in the community. He did say that he did not like how he was put to bed - he said he was cursed (at) when he got out of bed.

Section Q Question

One resident, who had been in a nursing home since the rule went into effect (2010), said she was not asked if she wanted to leave and get care in the community although she desperately wanted to leave. In fact, she kept asking when she would be able to leave and was told, over and over, "two weeks, two weeks." Another resident who lived in a nursing home for four or five years did not think that anyone was asked if wanted to leave. "Patients need more information. The question should be "where do you want to live..." or "do you want to leave the home. If someone says yes, then the staff should help them plan."

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."

Ms. D says that she was never asked whether she wanted to go back home. Whenever she asked when she could go home, nurses told her, "two weeks...two weeks." 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. Ms. D. complained to her advocates that no one in the home cared about her.

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

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'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."

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." Mr. R says that if someone answers yes to those questions, they should get help to plan leaving the home. He also said that "family should not speak if a patient can talk for himself." He added, "Nursing home staff should ask the question kindly, gently."