

# Difficult Decisions for Patients and Caregivers about Post-Acute Care and Why They Matter

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**NY StateWide Senior Action Council  
Telephone Teach-In  
May 19, 2020**



*Improving Health Care  
for Every New Yorker*

## The Quality Institute

United Hospital Fund works to build a more effective health care system for every New Yorker. An independent, nonprofit organization, we analyze public policy to inform decision-makers, find common ground among diverse stakeholders, and develop and support innovative programs that improve the quality, accessibility, affordability, and experience of patient care. Visit us at [uhfnyc.org](http://uhfnyc.org).

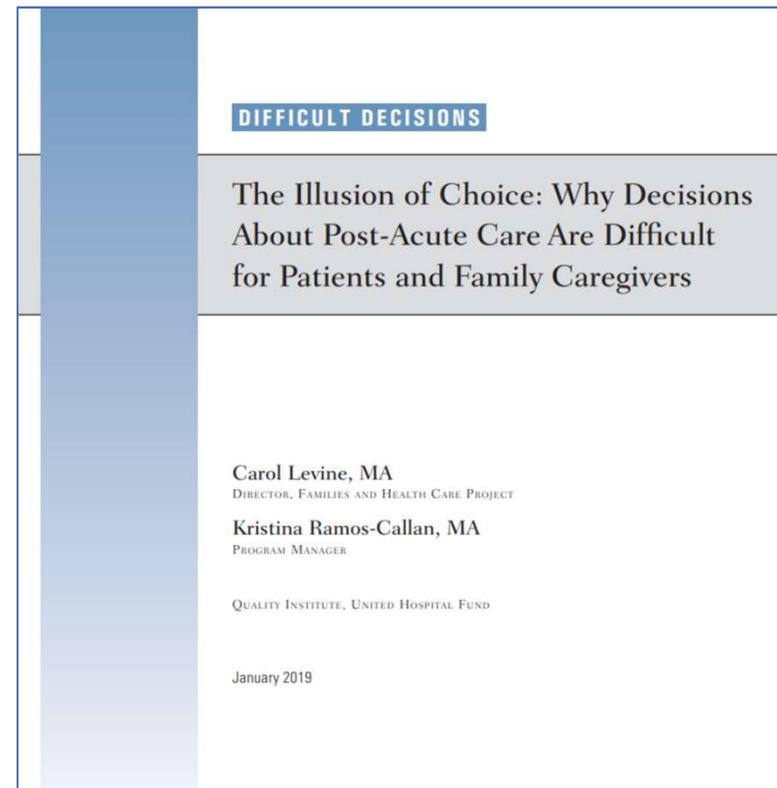
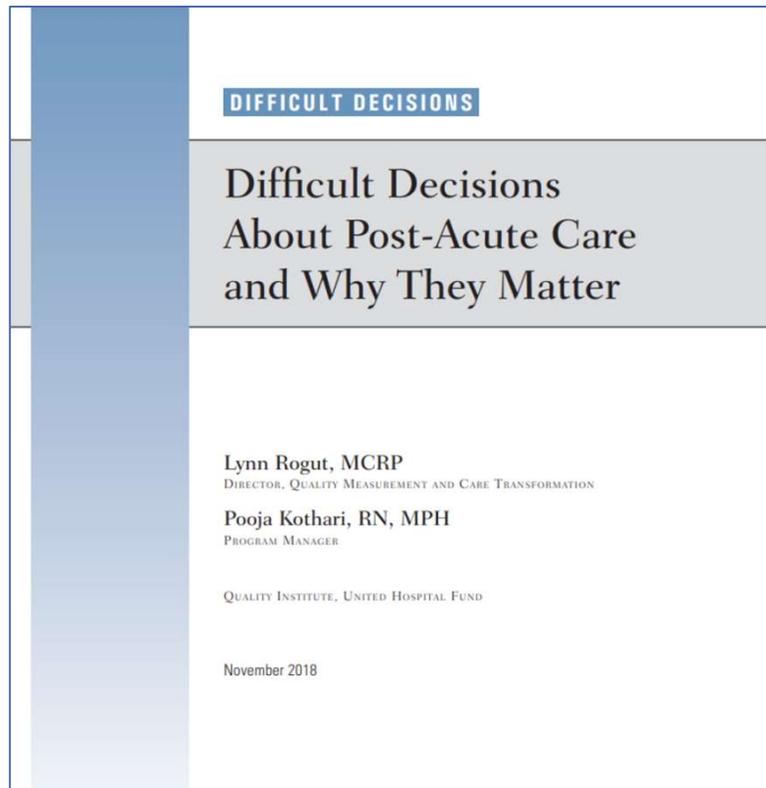
UHF's Quality Institute helps build a more effective health care system for every New Yorker by addressing continued quality, safety, and capacity challenges and by elevating the needs/priorities of patients, families, and consumers

[uhfnyc.org/initiatives/initiative/quality-institute/](http://uhfnyc.org/initiatives/initiative/quality-institute/)



Next Step in Care provides practical advice and easy-to-use guides for both health care providers and family caregivers that focus on transitions between hospitals, rehabilitation facilities, nursing homes, and home. Materials are free and available in English, Spanish, Chinese, and Russian at [nextstepincare.org](http://nextstepincare.org)

# UHF Difficult Decisions Report Series



<https://uhfnyc.org/initiatives/post-acute-care/>

\* Please note publication dates prior to COVID-19.

# Difficult Decisions Objectives

**To enhance understanding about:**

Why high-quality discharge planning is essential when decisions about post-acute care are needed, and why those decisions matter

Common barriers to informed decision-making

Publicly available quality information: how is it useful, and what are its limitations?

**Note:** UHF's study was conducted in 2018-19 before the introduction of federal and state regulatory changes in response to COVID-19, which may affect PAC decision making.

# About Hospital Discharge Planning

## What is it?

- “A process used to decide what a patient needs for a smooth move from one level of care to another.” – CMS
  - Commonly referred to as a **Care Transition**
- Not just planning for a physical change in care setting, but for a recovery period that may last a while

## Who does it?

- Ordered by a doctor but can be carried out by SW, RN, care manager or someone else. It is the responsibility of the hospital to ensure discharge planning takes place, as part of the Medicare program’s Conditions of Participation.

## When does it happen?

- It depends!
  - Planned admission – some steps can be planned ahead of hospital stay
  - Unplanned – hospital staff typically start discharge planning activities soon after admission; patient and family caregiver involvement usually starts a few days before the anticipated end of stay

# What is Post-Acute Care (PAC)?

PAC comprises care and services following hospitalization to continue recovery. PAC settings include:

Long-term  
Acute  
Care  
Hospital  
(LTACH)

In-  
patient  
rehab  
facility  
(IRF)

Skilled  
nursing  
facility  
(SNF)

Home  
with  
home  
health  
agency  
services  
(HHA)

Hospital  
at home

PAC at  
home

# More Context on PAC

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- PAC providers serve **vulnerable populations**
- Settings and providers are **siloed**
- **High volume, high cost** services; **evidence lacking** on what settings work best for which patients
- **Quality** of care **varies** among providers in NYS
- Although provider supply large enough in many areas of NYS to offer a range of choices, a host of **factors can constrain choice** of settings and providers, including COVID-19.
- **Until Sept. 2019, the onus was on patients/families** to research, evaluate, select a provider. COVID-19 flexibility waivers may reverse some gains, but effects unknown.

## Performance Ranges of NYS SNFs on Selected Short-Stay Measures, 2018-19

	<b>RATES</b>
Rehospitalization	0 – 43%
ED Visits	0 – 30%
↑ Function	16 – 100%
Antipsych med	0 – 10%

# Why Discharge Planning for PAC Can Be Challenging for Patients and Families



Demand for PAC is growing, but **many factors can constrain a patient's choice** of setting and provider. Yet, patients and families are often unaware of what those constraints are.



Decision-making can pose daunting challenges for patients and families. Yet assistance from **hospital staff can vary**.



Discharge planning is complex and time-sensitive. Hospital staff, patients, families feel pressure to reach decisions rapidly. Opportunities for **key steps or information to slip lead to communication gaps**.



Public information has limits, not especially helpful for trying to figure out the best option. Government websites best place to start, quality of the information is improving.

# Legal Framework Helps, Hinders, Dynamic

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## Federal

- Medicare CoPs, SSA Sec. 1802, Anti-Kickback Statute
- **IMPACT Act** – Sept. 2019: hospitals must assist patients by using/sharing provider quality information relevant to patient goals and treatment preferences
- **CMS COVID-19 Emergency Declaration Blanket Waivers (temporary)**

## State

- **Executive Order No. 202, 202.30**
- NYCRR Title 10, CARE Act of 2014



# **COVID-19 Temporary Waivers and Modifications: Some Examples**

## **CMS Federal Waivers**

- 3-day prior hospitalization rule for coverage of a SNF stay & 100-day limit
- Visitor and volunteer restrictions initiated
- Telehealth visits permitted in SNFs
- Discharge planning requirements to inform patients and families of choice and provide/review quality measures

## **NY State – E.O. 202.30**

- Mandatory testing of nursing home staff
- Hospitals cannot transfer COVID+ patients to NH or adult care facilities

# Legal Framework Not Aligned

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## The Bottom Line Is Complicated

Statutes, regulations, waivers:

- Safeguard choice but not access
- Protect patients from referrals influenced by remuneration (now waived by CMS), but not from risks of low-quality PAC
- CMS 2019 regulations enhanced support for PAC decision-making during discharge planning
- CMS emergency waivers and Executive Order give more flexibility to providers, which may result in less choice or more uncertainty for patients/family caregivers



# Why Is High-Quality Discharge Planning for PAC Important?

## Helps reduce risk for poor outcomes

- Readmission
- Complications
- Medication errors
- Gaps in care
- Falls

## Safe and adequate discharge plans are patient-specific

- Consider patient & family caregiver needs and preferences
  - Availability and willingness
  - Need for training
  - Worries and other concerns

# Caregivers' Most Common Concerns about Transitions to PAC

## Timing/Short Notice

- Need more time to consider the options
- Being told the plan, rather than included in it, may cause extreme distress

## Information Available

- PAC choice guidance may be limited, sometimes due to interpretation of anti-steering regulations.

## Misaligned Preferences

- Between patients and their family caregivers; between hospital staff and patients and their families (e.g. disagree about the choice of type of PAC setting or specific PAC facility)

## Care Refusal

- Patients may even refuse home health care (almost a third in one study (Topaz, M., et al., American Journal of Managed Care; 21(5); 2015.)

# 7 Things Patients and Families Should Know about PAC

## Choice Matters

- Quality of care varies by facility and agency.

## Quality > Location

- Location is important but quality of care can impact patient care outcomes

## Right to Appeal

- You have the right to appeal discharge, which is protected by NYS and federal regulations

## Insurance Limits Choice

- Choice limited by insurance to “in-network” providers and MA plans may limit LOS or home health visits

## SNF Unavailable?

- Pre-COVID-19 the best SNFs had few available beds. In the COVID-19 era, SNFs may have limitations on what patients they can take.

## Time is Short

- There could be little time to choose, sometimes less than a day. Pre COVID-19 facility visits are encouraged but not always realistic, during the crisis visits are all but impossible.

## First Choice, Best Choice?

- The first choice is important. Moves can be difficult once a patient is admitted, and may add stress for patients and family caregivers.

# Even More Difficult Decisions: Special Considerations for COVID-19

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Visitor limitations may make getting first-hand information about facilities even more daunting

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PAC facilities may limit what types of patients they are willing to take based on capacity constraints and resources available

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Media coverage of SNFs during COVID-19 may influence decision-making

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PAC patients in residential settings (e.g. SNF) will likely continue to be isolated/confined to their rooms

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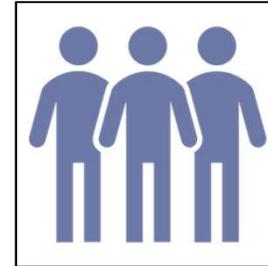
Patients and caregivers should assess tradeoffs of SNF v. home care and make best choice for their situation

# Many Factors Can Limit Choice



## Medical

- Need for specialized services  
(e.g., dialysis, bariatric, ventilator dependency)
- Costly drugs
- Mental Health conditions
- Substance Use disorders
- Cognitive problems, dementia
  - Likely to need LTC



## Social

- Age
- Immigration status
- Housing issues
- Behavioral issues
- Support network

# The Caregiver's Role in Discharge Planning

- Know when discharge will take place
- Prepare the patient's home
  - PPE
  - Food
  - Wifi or phone for telehealth needs
- Get education on care at home
- Provide or arrange for transportation



## Getting Home

- Coordinate home-based services
  - Note some services may have limited availability during quarantine
- Receive/set up/operate DME
- Manage medications
- Prepare special diets
- Assist with mobility and daily activities



## Medical - Nursing Tasks

- Be present for intake or initial visit or telehealth appointment
- Know whom to call if there's a problem
- Schedule services (RN, PT, DME)
- Provide or arrange for companionship/supervision



## Care Coordination

NSIC Discharge Checklist at:

[https://www.nextstepincare.org/uploads/File/Guides/Hospital/Discharge\\_Checklist/Discharge\\_Checklist.pdf](https://www.nextstepincare.org/uploads/File/Guides/Hospital/Discharge_Checklist/Discharge_Checklist.pdf)

*\*additions for COVID19*

# Family Caregiver Considerations for their Role in Discharge Planning and Care at Home



## Availability

- Easy distance from patient?
- Do you work? **Are you an essential worker?**
- Are you raising young children?
- Are you a caregiver to anyone else?
- Does your health affect caregiving?
- Can anyone else help?
- Are there other services involved or available (e.g., adult day care; home delivered meals; Personal Emergency Response System; Senior Center)?



## Training Needs

- ADLs (bathing, dressing, toileting, hygiene and grooming)
- Mobility and Transfer
- Medication
- Equipment
- Care coordination
- Transportation
- Household chores and other tasks



## Worries

- Stress level and coping
- Work life balance
- Caregiving's impact on relationships
- Managing medications
- Behavior (e.g. resisting care)
- Decision making, health and legal issues
- Safety and supervision (e.g. falls, wandering)
- Finances

Source: NSIC *What Do I Need as a Family Caregiver*

[https://www.nextstepincare.org/Caregiver\\_Home/What\\_Do\\_I\\_Need/](https://www.nextstepincare.org/Caregiver_Home/What_Do_I_Need/)

# Right to Appeal Discharge (NYS)

Patients have the right to appeal decisions made by doctors, hospital staff or managed care plans:



About when the patient is to leave the hospital



About being asked to leave the hospital too soon



About inadequate or inappropriate plans for care or other services needed after the hospital stay



If needed services are not in place

Source: Your Rights as a Hospital Patient in New York State - Section 2  
[https://www.health.ny.gov/publications/1449/section\\_2.htm](https://www.health.ny.gov/publications/1449/section_2.htm)

# Right to Appeal Discharge (Medicare)

## IM notice

- Receive "An Important Message from Medicare about Your Rights" notice within 2 days of admission (<https://www.cms.gov/Medicare/Medicare-General-Information/BNI/HospitalDischargeAppealNotices.html>)

## Patient Advocate/Navigator

- Facility based liaison between patients and health care providers on patient rights, complaints, grievances, and conflict resolution.

## BFCC-QIO

- New York's Beneficiary and Family Centered Care-Quality Improvement Office <https://www.bfccqioarea1.com/>.
- Other states: <http://qioprogram.org/contact-zones>.

## Center for Medicare Advocacy

- Legal analysis, education, and self-help packets for many appeals [www.medicareadvocacy.org](http://www.medicareadvocacy.org); and **COVID-19 info:** [Advocate's Guide to COVID-19 changes](#)

## Medicare Rights Center

- Counseling, advocacy, and educational programs to help ensure access to care <https://www.medicarerights.org/>

## NYS Long Term Care Ombudsman Program

- State advocate for older adults and persons with disabilities in residential facilities. <https://www.ltombudsman.ny.gov/>; for other states see [www.ltombudsman.org](http://www.ltombudsman.org).

# What's Important to Family Caregivers when Choosing a PAC Facility?

<b>Location</b>	<ul style="list-style-type: none"><li>• Convenient for family/friends; some willing</li><li>• to go further for specific services</li></ul>
<b>Intensity and Availability of Services</b>	<ul style="list-style-type: none"><li>• Frequency of physical therapy; any special services available? e.g. specific disease supports (e.g. ALS), on-site dialysis, respiratory therapy, ventilator</li></ul>
<b>Ongoing Care</b>	<ul style="list-style-type: none"><li>• For patients who won't be able to go home,</li><li>• is the PAC setting appropriate for subsequent transition to long-term care?</li></ul>
<b>Finances</b>	<ul style="list-style-type: none"><li>• Is the facility in-network? What will insurance cover - how many days; at what cost? Will the facility take patients with expensive medication needs?</li></ul>

# How People Usually Get Information When Choosing PAC

## Wait for it

- Some did little to no research, waiting for guidance from hospital staff that they typically didn't get

## Major Project (w/ reinforcements)

- Some made a full scale project of visiting facilities, combing websites, and consulting friends

## Know a Professional

- Asked friends with professional health care experience (RN, PT, others) for recommendations, to investigate options, and help choose. Some even bring friends who were ex-staff on visits.

## Word of Mouth

- Word of mouth recommendations are popular but sometimes unreliable due to outdated expectations of care (e.g. length of stay, staffing ratios, managed care network participation)

# Information Barriers for Patients and Families Choosing PAC

## Language barriers

- Online info and reviews often only in English

## Computer Literacy

- Many relied on younger family members or friends to help them do research and to translate information, citing language and computer literacy barriers

## Marketing v. Information

- Websites were largely promotional and lacked specifics on services, activities

## Understanding Quality Measures

- Some patients and families who did use quality rating websites like Nursing Home Compare found the ratings unhelpful because they didn't seem relevant to short-term stays

## Timeliness

- Consumer review sites like Yelp, Google user-reviews, were seen as helpful because they described people's real, recent experiences

# Available Information Sources and Tools for Learning about PAC Quality

## Information sources about PAC providers

- **CMS**
  - Nursing Home Compare
  - Home Health Compare
- **State Nursing Home quality websites**
  - NYSDOH Nursing Home and Home Health Profiles
  - NYSDOH Nursing Home Quality Initiative
- ProPublica's Nursing Home Inspect
- LTCCC
- Social media – Google, Yelp, Facebook

## But publicly available information has limitations

- Many websites, lots of technical measures, **less emphasis on aspects of quality that consumers find meaningful** – e.g. quality of life, staffing adequacy, care coordination and communication
- Additional gaps – e.g., facility characteristics, patient/family experience and reviews, staff qualifications, access to specialists, staff interpersonal skills

# CMS Nursing Home Compare SNF Star Ratings

- Users can compare quality of care at up to 3 facilities at time

	SNF A <span>x</span>	SNF B <span>x</span>	SNF C <span>x</span>
	Overall rating ⓘ: ★★★★★ Much Above Average	Overall rating ⓘ: ★★★●● Average	Overall rating ⓘ: ★●●●● Much Below Average
Quality of resident care ⓘ	★★★★★ Much Above Average	★★★●● Average	★★★★★● Above Average
Short-stay quality of resident care ⓘ	★★★★★ Much Above Average	★★★●● Average	★★★★★● Above Average
Long-stay quality of resident care ⓘ	★★★★★ Much Above Average	★★★●● Average	★★★★★ Much Above Average

Source: <https://www.medicare.gov/nursinghomecompare/search.html>

# CMS Nursing Home Compare Short Stay Measures

	SNF A	SNF B	SNF C	NEW YORK AVERAGE	NATIONAL AVERAGE
<b>Short-stay quality of resident care</b> 	 <b>Much Above Average</b>	 <b>Average</b>	 <b>Above Average</b>		
<b>Measures used to calculate the star rating - Short-stay residents</b>					
Percentage of short-stay residents who were re-hospitalized after a nursing home admission. Lower percentages are better.	18.6%	19.0%	17.2%	20.4%	22.6%
Percentage of short-stay residents who have had an outpatient emergency department visit. Lower percentages are better.	6.8%	7.0%	7.2%	8.8%	10.7%
Percentage of short-stay residents who got antipsychotic medication for the first time.  Lower percentages are better.	0.2%	1.6%	0.0%	1.5%	1.8%

Source: <https://www.medicare.gov/nursinghomecompare/search.html>

# NYS DOH Nursing Home Profiles

- Search for facilities by Region or County
- Review facility profiles one at a time, or side-by-side
- Compare performance on short and long-stay measures, find specialty nursing homes, and view inspection information.
- Review quality measures in five domains
  - Preventive Care
  - Quality of Life
  - Quality of Care
  - Resident Safety
  - Resident Status

[https://profiles.health.ny.gov/nursing\\_home/index](https://profiles.health.ny.gov/nursing_home/index)

**Department of Health NYS Health Profiles**  
Find and Compare New York Health Care Providers

Hospitals ▾ Nursing Homes ▾ Home Care ▾ Hospice ▾ Adult Care ▾ Other Providers ▾

### NYS Nursing Home Profiles

We make it easy to find quality and safety information on New York's nursing homes.

**Nursing Homes**

- Absolut Center for Nursing and Rehabilitation at Aurora Park, LLC  
292 Main Street, East Aurora, NY 14052
- Absolut Center for Nursing and Rehabilitation at Endicott, LLC  
301 Nantucket Drive, Endicott, NY 13760
- Absolut Center for Nursing and Rehabilitation at Gasport, LLC  
4540 Lincoln Drive, Gasport, NY 14067
- Absolut Center for Nursing and...

Search for Zip, City, or Name

Compare quality, find specialty homes, and view inspection information! Nursing Home Profiles provides useful information about every nursing home in New York State. Examine nursing performance through a set of metrics that look at:

- Quality of care received
- Quality of life achieved
- Safety of residents
- Preventive care practices
- Inspections and complaint information

Learn more about selecting a nursing home, long-term care alternatives, and average costs by region. The Department of Health provides educational materials for you and your family. Download our [consumer guide for selecting nursing homes](#), or get more information about [assisted living](#) or [community-based care options](#).

**My Providers** [compare these](#)

To compare facilities, click on the icon next to each facility's name.

[Print these](#) [close](#)

**Further Reading**

- [About Nursing Home Performance](#)
- [Consumer Guide: Selecting Nursing Homes](#)
- [About Nursing Home Services](#)
- [Nursing Home Resources](#)
- [Alternatives to Nursing Home Care](#)
- [Submit a Complaint About a Nursing Home](#)

# NYS DOH Nursing Home Profiles

[https://profiles.health.ny.gov/nursing\\_home/index](https://profiles.health.ny.gov/nursing_home/index)

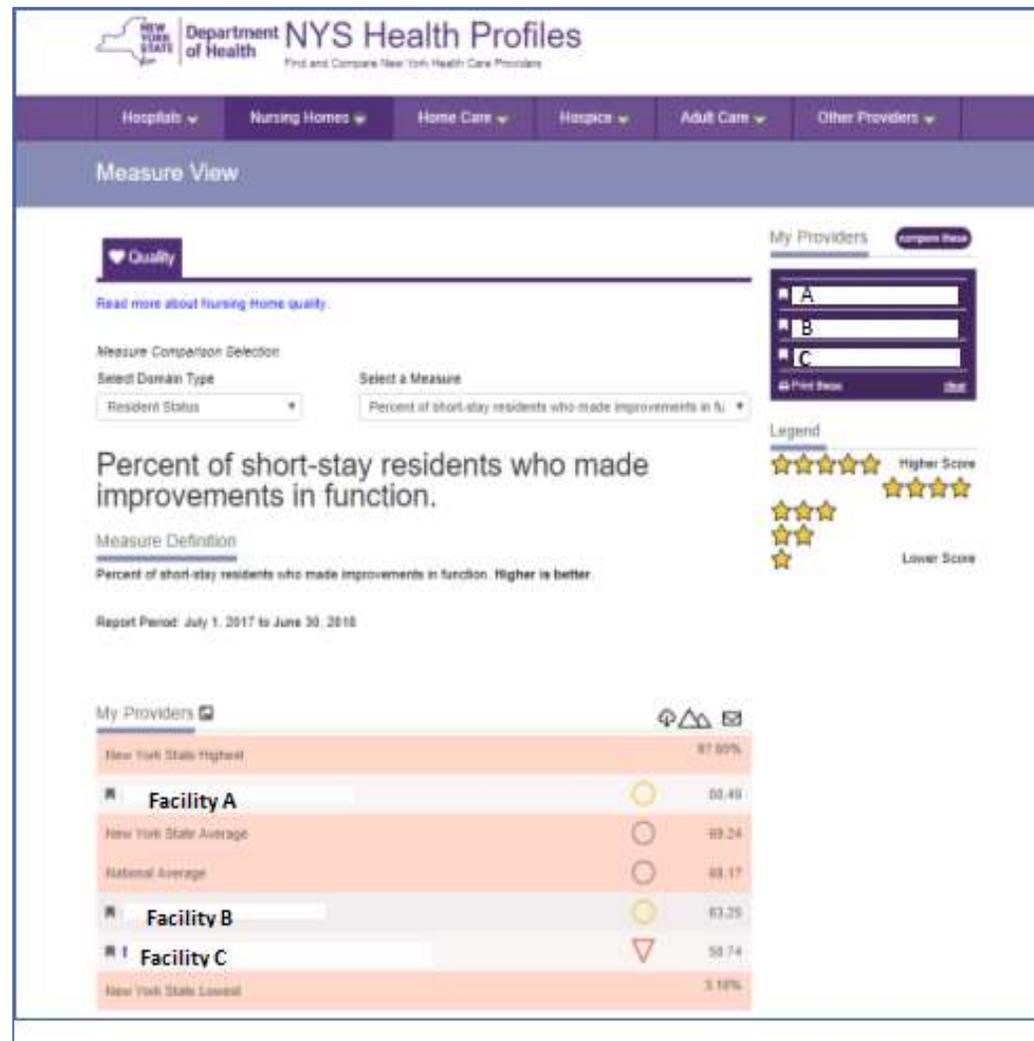
Sample comparison

Domain:

Resident Status

Measure:

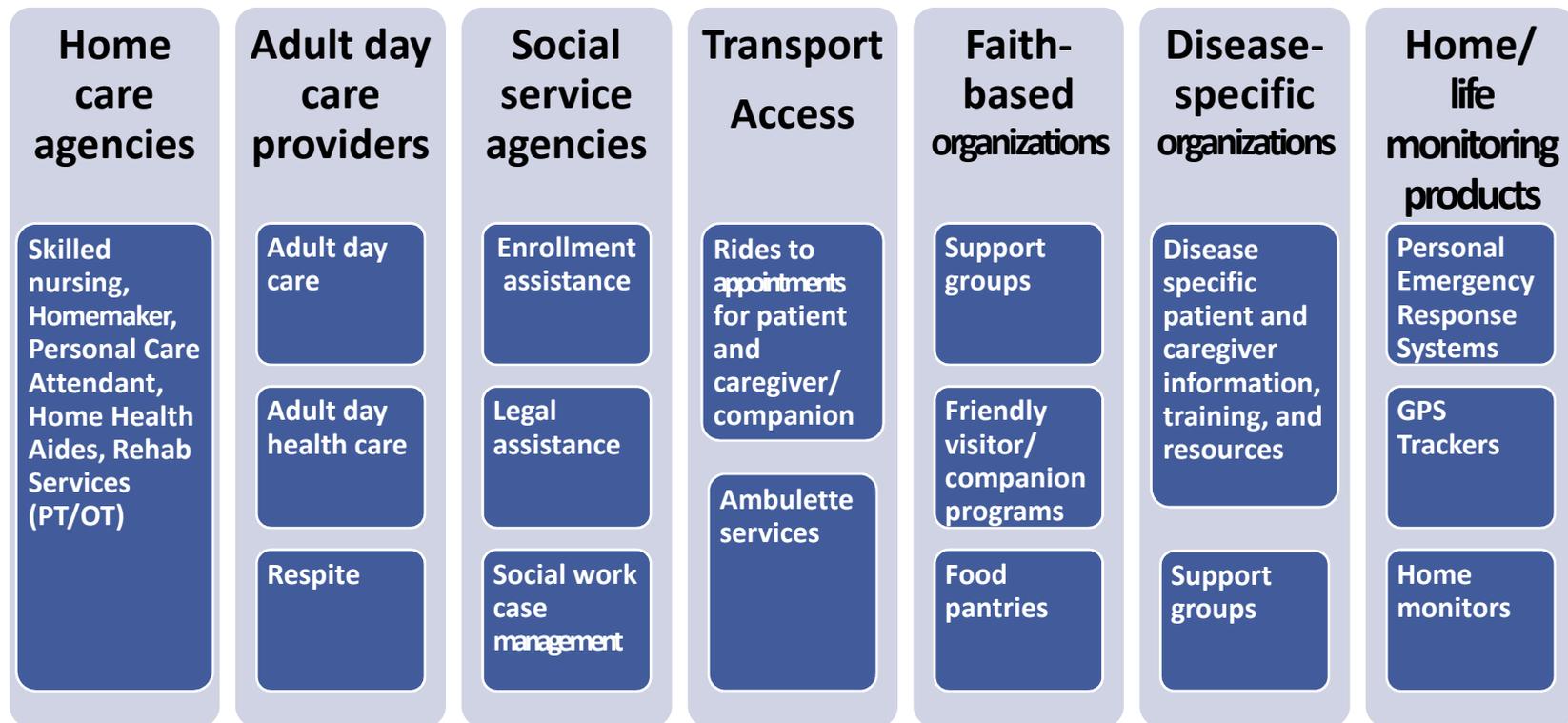
Percent of short-stay residents who made improvements in function



# Resources for Patients & Caregivers

## Post-Discharge

Transitions don't end when the patient gets home; they can last for weeks or months. Anticipating patient and caregiver needs in an extended transition may include identifying community agencies that can help support the care plan.



**Keep in mind that resource availability may be different due to COVID-19.**

# Summing Up

- Family caregivers provide essential emotional, physical, and other kinds of assistance for people who need PAC or LTC.
- They need decision support and assistance to be able to do this demanding job.
- Care managers are the link to many medical and nonmedical services and supports for both patients and family caregivers.
- Helping patients and family caregivers access, understand, and use the available resources can make everyone's role easier.
- During the pandemic, informed decision-making about PAC may be even more challenging for patients and families.
- Information resources and tools can help:
  - UHF's Next Step in Care ([www.nextstepincare.org](http://www.nextstepincare.org)).
  - CMS Compare (Hospitals, Nursing Homes, etc.)
  - NYS Health Profiles (Nursing Homes, Hospitals, Home Care, etc.)

# Questions?

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