



Behind Closed Doors: Understanding the Resident Experience

A SURVEY OF RESIDENTS LIVING IN
LONG-TERM CARE FACILITIES

OVERVIEW

Individuals living in long-term care facilities deserve high-quality person-centered care, to experience quality of life, and be treated with dignity and respect. The National Consumer Voice for Quality Long-Term Care (Consumer Voice) surveyed residents of long-term care to find out what life is really like for them on a day-to-day basis. We asked questions regarding whether they are treated with dignity, have access to technology, and the issues that impact their daily life like staffing, food, and activities. We also asked questions about whether they are able to live life on their own terms.

Consumer Voice received answers from more than 450 residents and their responses were eye-opening. Three-fourths of the respondents live in skilled nursing facilities. The remaining quarter live in assisted living facilities. Nearly 40 years after passage of the Nursing Home Reform Act of 1987, half of all respondents told us that their quality of life got worse after moving into their facilities.

The report found that many residents do not view their facility as their home, even in the best circumstances. Residents who described having a better quality of life often attributed it to adapting to the facility's schedule rather than the facility adapting to theirs, or to having family support in understaffed environments and knowing their rights well enough to advocate for themselves. The report also found a widespread lack of autonomy, with many residents noting that chronic understaffing affected their daily routines and overall quality of life. While some comments showed that respectful, timely, rights-centered care is possible, many more residents reported that their rights, needs, dignity, and preferences are not being consistently upheld.

Respondents represent more than 40 states and live in government, non-profit, and for-profit facilities. It is important to note that while the online survey represents a wide variety of residents, it only represents those residents who have the ability to respond to a survey, with access to technology, and, when needed, had assistance from someone who took the time to help them.ⁱ

Their answers reflect a spectrum of experiences. While some residents do seem to be receiving the high-quality care to which they are entitled, many are not. The more positive answers illustrate that person-centered care is possible. However, in 2025, we would hope that the number of residents having positive experiences would be considerably higher.

The results showed that 76% of residents were not always getting the care they need when they need it. More than one-third of respondents reported that their food is rarely or never appetizing. Almost half (43%) told us that it is difficult to live life on their own terms at their facilities. This data does not reflect the person-centered care that we expect.

Overall, we learned that while some facilities are living up to expectations, many are not. This report highlights themes identified in resident responses, such as poor staffing levels, feelings of loneliness, and a lack of autonomy and control over their lives. To hear directly from residents, we've included a sample of quotes residents provided in response to the survey. As one resident noted when asked about her quality of life, "we have gone from feeling we have a home, to a room in an institution."

KEY FINDINGS

Of the residents who responded to the survey:

- **50%** say their quality of life got worse after moving into their facilities.
- **32%** say they are only sometimes, rarely, or never treated with dignity or respect in their facilities.
- **19%** say their opinions and preferences about their daily care and routines are rarely or never considered.
- Only **24%** say they always get the care they need in their facilities when they need it.
- **34%** report that the food at their facilities rarely or never looks or smells appetizing, with **25%** reporting they are rarely or never offered an alternative.
- **25%** say the activities offered by their facilities are rarely or never interesting or engaging.
- **97%** who have visitors can see their visitors when they want to see them.
- **40%** do not have a family caregiver.
- **39%** report that a lack of transportation prevents them from participating in community events.
- **52%** of respondents are able to participate in religious services of their choice, though this appeared truer for members of certain religions than others.
- **32%** report that members of their community visit their facilities to participate in or host events less than once a month, if at all.
- **50%** report that they have access to technology when they want to use it with **58%** reporting that they use technology daily.
- **36%** report there is rarely or never enough staff in their facilities to meet their needs in a reasonable amount of time.
- **43%** report that it is somewhat or very difficult to live life on their own terms at their facilities.

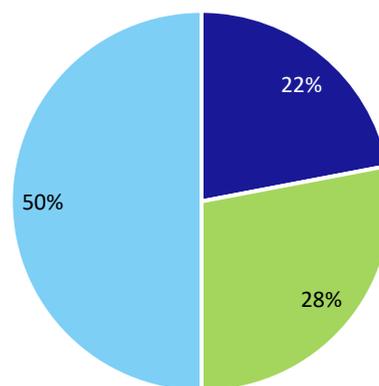
QUALITY OF LIFE

Everyone moving into long-term care is entitled to and should expect quality, person-centered care. In fact, federal nursing home regulations [emphasize](#) that “quality of life is a fundamental principle that applies to all care and services provided to facility residents,” and that, “each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being.”

Yet, half of the people who responded to our survey report that their lives got worse after moving into their facilities. They cite reasons that include serious weight loss due to inedible food; poor care due to lack of staff; unresolved negative changes that happened during COVID-19; and a lack of consideration for their disabilities.

A decline in quality of life is neither acceptable nor should it be inevitable for people living in long-term care. While half of our respondents, 50%, reported a decline in quality of life, 22% report that their lives in long-term care have improved, which illustrates that high-quality care is possible and it is possible for residents to live rich lives in their facilities. Another 28% of residents told us that the quality of their lives stayed the same.

How Has Your Quality of Life Changed?



■ It has improved ■ It has stayed the same ■ It has gotten worse



Resident comments include:

"My preferences and wishes are ignored..."

"I feel like it's a prison. Throw you in a room and throw away the key and let us rot away."

"Residents are basically confined to our rooms, no social activities at all."

"Your life is not your own here."

"Lack of good food, security, loneliness."

"Lack of staff/care, staff with training, bad attitudes and excuses."

"Staffing is down, food quality has gone from five star to one star, service by staff has gone from excellent to dismissive and retaliatory..."

"The nutrition is very poor and life enrichment activities are nonexistent."

"Although having assistance and care close at hand (sometimes) is an improvement in terms of my safety, in other ways my quality of life is much worse. The food is often unrecognizable and lacking in nutritional value. In addition, I'm lucky if I get a shower once a week and then only when I ask and insist many times..."

While many of the comments to this question came from residents who felt their quality of life declined after moving into their facilities, there were some comments from residents whose lives improved:



Resident comments include:

“My facility has a top-notch staff team that strives to maintain our care and dignity.”

“I do not feel so alone.”

“The nursing staff provides very good care.”

“It is better because I had no one to take care of me.”

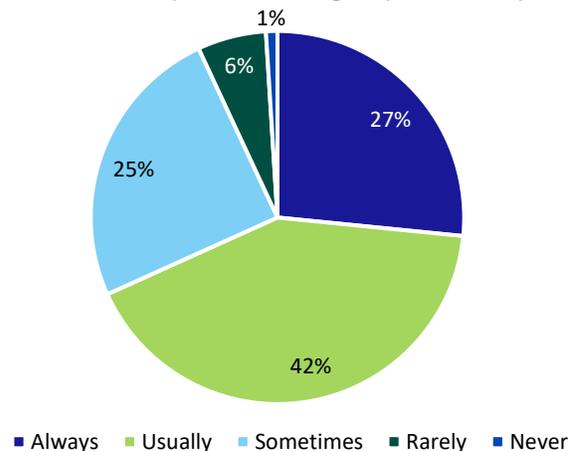
DIGNITY AND RESPECT

People who move into long-term care are entitled to the same dignity and respect as everyone else. [Federal nursing home guidance](#) states that residents have the right to a dignified existence and that “a facility must treat each resident with respect and dignity and care for each resident in a manner and in an environment that promotes maintenance or enhancement of his or her quality of life, recognizing each resident’s individuality.”

Yet, many residents with whom Consumer Voice have spoken over the years have talked about the lack of dignity they feel after entering their facilities. They have told us they never expected to “stop being a person in some people’s eyes,” but feel that when they entered their facility, they “left their dignity at the door.”

When asked whether the staff treat residents with dignity, just over a quarter of respondents, 27%, answered they always feel treated with dignity by staff. Forty-two percent answered they are usually, but not always, treated with dignity. Another 25% said they are only sometimes treated with dignity and seven percent answered that they are rarely or never treated with dignity.

Do staff treat you with dignity and respect?



As residents have explained to us over the years, even being treated poorly on occasion has a lasting impact on them. Being treated like a number rather than a person, being overlooked, being treated rudely, particularly when they are vulnerable and reliant on staff, disempowers them, it has an impact on their well-being even if it doesn’t happen every day. One resident explained, “it’s the specific moments when your dignity gets trampled on.”

Residents responding to our survey told us they are not always given choice in their care, that staff are too busy to notice them, and that, at times, they are treated like they are dumb or too stupid to understand. Several residents said that while their Certified Nursing Assistants (CNAs) try and treat them better than facility leadership, they are often overworked and tired.

Residents also noted a difference in treatment between their regular aides and agency staff who come in not knowing anyone. They are treated better by the staff who know them and their routines. Many cited understaffing and turnover of staff as reasons that they're not always treated with dignity.



Resident comments include:

"Management doesn't care. Line staff does."

"The regular staff does but the agency sometimes don't speak or let us know what's going on."

"If the staff sees that your family comes to see you then they are nice to you."

"Permanent staff did, agency staff are useless"

"It depends on the staff member or sometimes depends on their mood."

"It depends on what staff you are talking about."

"A few staff are dedicated but the administrators care nothing about our welfare."

"We are bullied when trying to speak up for ourselves and our rights."

"A lot of staff are hired just for a day from staffing services, they don't care."

"There is a long time waiting to address basic needs or issues, there is no one around usually if I need something."

"Staffing is very irregular, hard for the facility to keep staff, so there's turnover and registry or contracted staff who are not consistent. Most are good, however even if a few are not good, it's impactful."

"I'm treated with dignity and respect when they show up, but it can take a LONG time for them to show up. Sometimes they talk to me like I am a child."

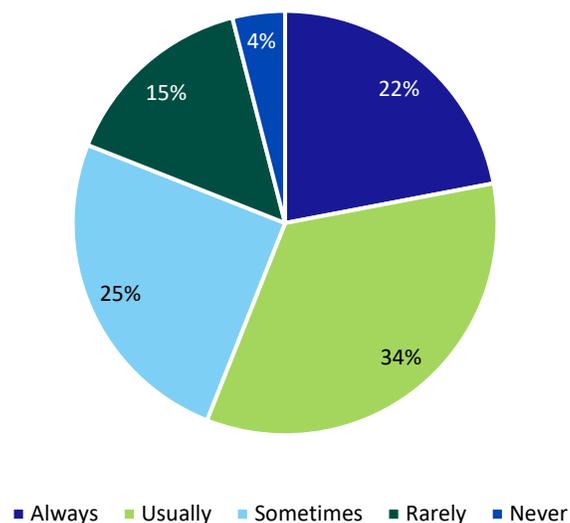
OPINIONS AND PREFERENCES

Person-centered care involves listening to residents and considering their opinions and preferences in determining their daily care and routines.

When asked whether their opinions and preferences were taken into consideration, residents' answers ranged widely. While 22% said that their opinions and preferences were always considered, 20% said they were rarely or never considered. Thirty-four percent said their opinions and preferences were usually considered with 25% saying they are only sometimes considered.

Residents commented that staffing is a big issue in this area. Many noted that staff convenience supersedes residents' opinions and preferences. They talked about how often they are not asked their opinions, and their needs are not taken into consideration.

Are your opinions and preferences taken into account?



Resident comments include:

"Management arranges life for their convenience not our benefit."

"I am not informed when I have care plan meetings."

"Showers are given at the staff's convenience."

"I don't get a choice of what time I want to get ready for the day or what I want for my meals..."

"I would like to be heard so that my needs can be met..."

"The place, a nursing home, runs on the schedule of the staff and hardly ever are we asked how we would like our care integrated into a schedule of our own design."

"They do not follow up on my concerns."

"We are chronically short staffed which affects care."

"They don't ask when I'd like to get up or what time I can choose to shower."

"Staff dictates when care is given."

"They ask, they don't provide. Waking us up at 4 or 5 am for medications and dressing for breakfast is not following our preferences."

"I often have to repeat my preferences over and over because the staff changes so often."

GETTING THE CARE YOU NEED WHEN YOU NEED IT

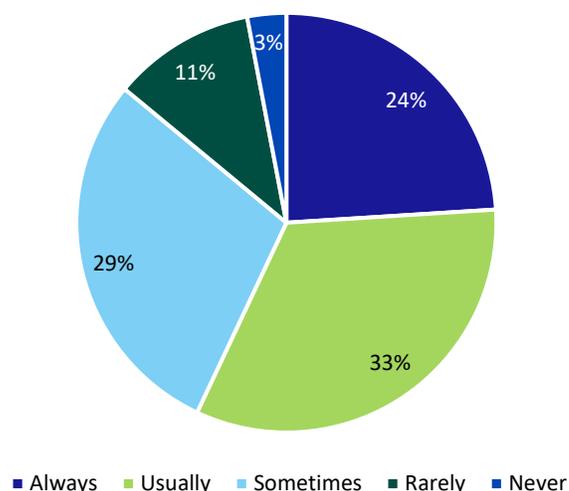
Most people enter long-term care expecting their needs will be met and they will receive the care that they are entitled to.

When we asked residents if they are getting the care they need when they need it, just under one-fourth of respondents said they always receive the care they need when they need it. Thirty-three percent answered usually. Twenty-nine percent answered sometimes and 14% said rarely or never. Even those residents who answered that they usually or sometimes receive the care they need when they need it are still being left behind at times.

Many residents talked about short staffing impacting when they receive their care and they talked about the long delays they frequently experience.

Many residents also mentioned the long wait times and indignity that they suffer on a regular basis due primarily to understaffing.

Are you getting the care you need when you need it?



Resident comments include:

"I had a three hour wait or more after pressing emergency button to get medication."

"As long as 45 minutes to respond to any patient call bell."

"They are frequently understaffed."

"The call button issues of not being answered are not being resolved."

"Last month I started having symptoms of what turned out to be norovirus. When I called for help I was told to 'ride it out.' I eventually dialed 911 and subsequently spent three nights in the hospital."

"Call lights take forever to be answered at times. Sometimes as long as 50 minutes."

"Long waits for call light."

"I have to sit in urine for periods of time."

"The wait time ranges from 10-50 minutes, but I can do a lot for myself, so I can imagine it is more difficult for those who cannot do much for themselves."

"We pay between \$15k and \$18k a month for care, chronic understaffing means wait times for care like bowel and bladder care."

"We are short staffed, staff are underpaid, overworked, and frustrated."

"The level of care is not what they advertised and agreed upon when I signed my contract."

"Going three days without being washed up is a little ridiculous."

FOOD

When speaking with long-term care residents, inevitably the topic of food comes up. Food plays a big role in everyone's life and people living in long-term care are no exception. For many residents, mealtimes help break the monotony of the day. It is something they want to look forward to. Yet, for many residents, the food they are served in their facilities is repetitive, unappealing, and nutritionally lacking.

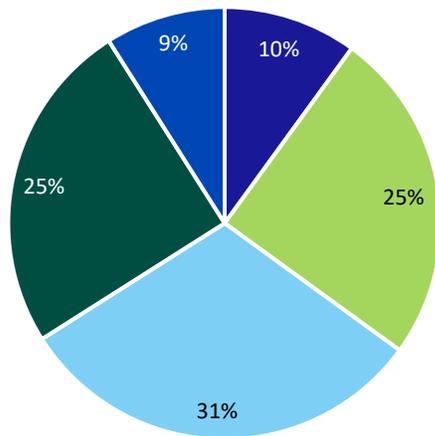
We asked several questions about food in this survey. Although not universal, responses illustrated that many residents are not being served appealing and appetizing food at the correct temperature and are not offered alternatives when they don't like the meal served.

Many residents went as far as to compare their food to food served in prison, they said "eat what you are served and deal with it." Many report they are never served fresh fruits or vegetables. Others complained about having no say on the menu or being denied the food they need for their dietary needs.

Only one-third, 35%, of respondents told us their food usually or always looks and smells appealing, with 65% stating their food is only sometimes, rarely or never appealing (31% and 34% respectively).

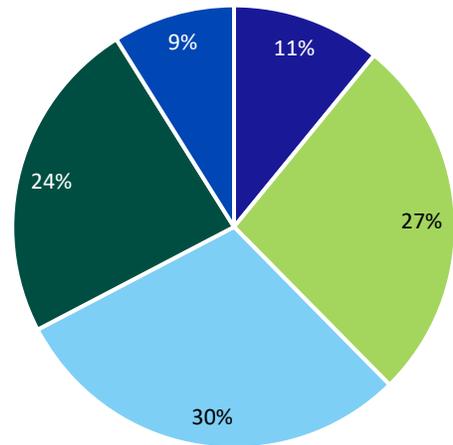
Only 11% of respondents said their food is always served at the right temperature, and 27% said it is usually served at the correct temperature. Thirty percent sometimes receive food at the right temperature and 33% said that it rarely or never arrives at the correct temperature.

Does your food look and smell appetizing?



■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never

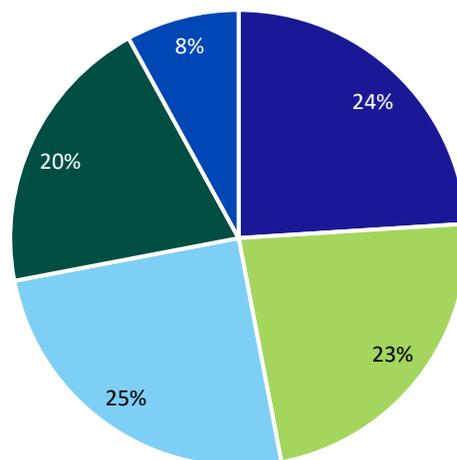
Is your food served at the right temperature?



■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never

We received a slightly more positive response when asking whether people are offered alternatives when they do not like the meal being served. Almost half of respondents are usually or always offered an alternative. However, in their comments many residents acknowledged that while they receive alternatives, the alternatives are often unappealing or repetitive. Twenty-five percent of respondents are only sometimes offered alternatives, and almost 30% of residents are rarely or ever offered any alternative meal at all.

If you don't like your meal, are there alternatives offered?



■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never



Resident comments include:

"Nothing looks appetizing or tastes good."

"The food lacks nutritional value, not nearly enough vegetables and rarely any fresh fruit."

"Burnt, overcooked, undercooked, or raw."

"Heavy carbs, salt, and sugar. No fresh fruits or vegetables."

"Food is cold, salad is wilted, portions have decreased in size considerably since new owners."

"I would like to have some fresh fruit, real cheese, and real potatoes."

"No fresh fruits or vegetable ever, too many carbs."

"Alternatives are only offered 2 to 3 times a week and then it is the same thing all the time. Those meals do not include vegetables or fruit either."

"They don't understand and don't ask about my special diet due to Crones Disease."

"Residents do not have any say in the menu. No one collects feedback about the food quality or variety."

"It's sad to say, but I think jails have better food."

"Most of the time it looks like dog food. Also, the past three nights I have gotten live roaches on my dinner trays so I won't eat anything at all after seeing them run across my dinner tray."

"My blood sugar has been out of control ever since institutionalized living."

There are residents, however, who spoke highly of the food service in their facilities, illustrating that it is possible for long-term care facilities to serve appetizing, appealing meals that meet their needs.



Resident comments include:

"The main kitchen staff are very talented cooks."

"Food is excellent. Staff are very helpful and pleasant."

"The food is aligned with my care plan dietary needs."

"It is better than most facilities."

"It's not five-star quality but it's good, solid home-type cooking."

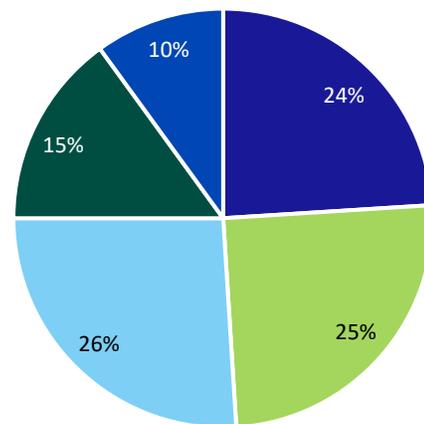
ACTIVITIES

Another important part of life in a long-term care facility that contributes to a resident's quality of life is the activities that are offered. We asked residents whether the activities offered by their facilities were engaging and interesting. We also asked if they were able to participate in similar interests and activities as they did before entering their facilities. We asked if residents are able to participate in the activities they want to participate in, and we asked about residents' favorite activities.

Forty-nine percent of respondents answered that they usually or always have engaging activities. Twenty-six percent said they sometimes have interesting and engaging activities offered, and the remaining 26% answered they rarely or never have engaging or interesting activities available to them.

Some residents told us they are sometimes excluded from activities because of their disabilities. Others told us that their facilities offer very few activities and always repeat the same ones. Some complained that there is very little interaction offered at their facilities, and some noted that age/acuity appropriate activities would be welcomed.

Are the facility's activities interesting and engaging?



■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never



Resident comments include:

"Need more activities and outings."

"They keep repeating Bingo, so it's played almost every single day. Some musicians who put people to sleep. Some of the activities are during times when more than half of the residents haven't even been able to get washed/dressed yet or are being served dinner so we can't participate. We have asked for the times to be changed but our requests fall on empty ears."

"I am not a regular participant because of my disabilities."

"Too many repetitive things that no one wants to do."

"Residents should be asked about the activities they wish to participate in."

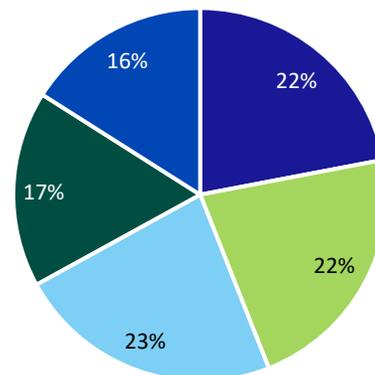
"It's only a month before and after state survey is here that a new or engaging activity is added but it gets taken off rotation pretty quick after survey time... Also, activities are not allowed for those who can't leave their room. A book, activities book, or magazine is offered twice a month... Activities told us that the snacks are only for residents who want to join them in the dining room. I'm physically not able to leave my bed sometimes, like many other residents, which means we have become ineligible for a simple treat that many of us have not had for years."

"There are no activities available."

"Nothing is offered for those who must stay in bed."

When asked whether they are given opportunities to engage in similar interests and activities as they did before they entered long-term care, 44% said they usually or always are, but 23% said only sometimes and 33% answered rarely or never can they engage in the types of activities and interests they did before they entered their facilities. Some noted that they only had options that the facilities chose for them, and others cited transportation as an issue. For many residents wanting to go to an activity, social engagement, or in some cases, even a doctor's appointment, they must rely on outside transportation - family or friend, or paid transportation service. Unfortunately, that makes it prohibitive for those without family or friends to assist them, or lack of funds to pay for transport.

Can you engage in similar activities as before you entered long term care?



■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never



Resident comments include:

"I can't go to the library or the mall or any kind of shopping. Not allowed to go to a park. I used to do all kinds of volunteer work; I can't do that anymore either. I'm not allowed to leave the building."

"Van rides are rarely offered."

"We are given a hard time if we have plans to go out with family or friends."

"I would love to be driven around town to see different sights rather than be stuck inside every day. I'm wheelchair bound so my family can't drive me in their cars. Maybe the nursing home could set up monthly drives in their mobile vans for wheelchair bound residents."

"I feel this facility should have transportation for those who can get out to stores, etc."

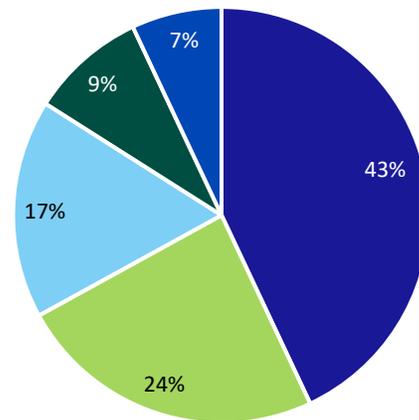
"My personal computer allows me to do a lot of things I love."

"Just what they choose and it's usually boring stupid stuff for children."

"We have not had an activity in weeks."

In terms of the activities that do exist that residents want to participate in, a reassuring 67% said they are always or usually able to attend the activities they choose to participate in. Seventeen percent said they can sometimes attend the activities they want to attend but concerningly, 16% said they're rarely or never able to attend the activities they want to participate in.

Are you able to attend and participate in the activities you want to?



■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never



Resident comments include:

"I attend if they don't schedule showers or beauty shop appointments at the same time and if they remind me they're occurring."

"I am blind, rarely do the staff let me know about activities."

"Many residents can't attend, not enough caregivers to push them to events."

"No one tells me and no one asks if I want to go."

"Sometimes I'm not gotten out of bed in time for the activity." "Sometimes I have to go to an activity with a wet diaper. "

"There are no activities. There have not been in a long time."

"If they remember to come get me."

"If we are notified of the activities when they are occurring – we often miss them due to not enough notification."

"I'm in a wheelchair now and can no longer get there without help."

The majority of comments shared by residents referenced not having engaging activities or being unable to participate in activities. However, some residents shared that their facilities are doing a good job of offering engaging activities that residents enjoy and that their activities directors work directly with residents to engage them.



Resident comments include:

"Activities director meets with new residents to find interested activities and tries to connect those who have similar interests and form groups, book club, bridge, gardening, etc."

"We have a vegetable and flower garden."

"Activity director plans items that draw residents – baseball games, farmers markets."

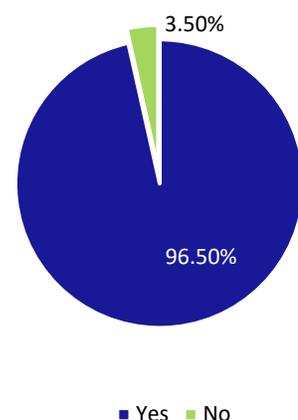
"We have great activities here."

VISITATION

Visitation is an issue that is hugely important for all residents of long-term care. We asked whether residents are able to see visitors whenever they wish and 97% of respondents stated that, yes, they are able to see visitors whenever they wish.

However, when commenting, many respondents spoke of the fact that they don't have visitors to come see them or that their family and friends live far away. This question serves as a good reminder that many residents feel isolated or alone in their facilities without friends and family visiting them. While 3% of respondents answered that they do not always have access to their visitors, citing hourly restrictions and shut downs that continue related to flu and COVID-19 outbreaks, many comments that we received spoke to this.

Are you able to see visitors when you wish?





Resident comments include:

"I don't have many."

"I have no visitors."

"They even shut down my floor for the flu... a week before a covid shutdown for 14 days."

"Between 6am and 10pm."

"I am physically too far for my friends and family to visit."

"I don't often have visitors."

"My complaint was substantiated when nurses were telling my visitors they were not allowed to visit more than one person and not allowed to visit after 8pm. Signs on the front door dictated between 9am and 4pm."

"Facility put in restrictive hours for visitation – violate the law daily."

"They did and do continue to keep my family away when there is a COVID outbreak, even though they are not supposed to."

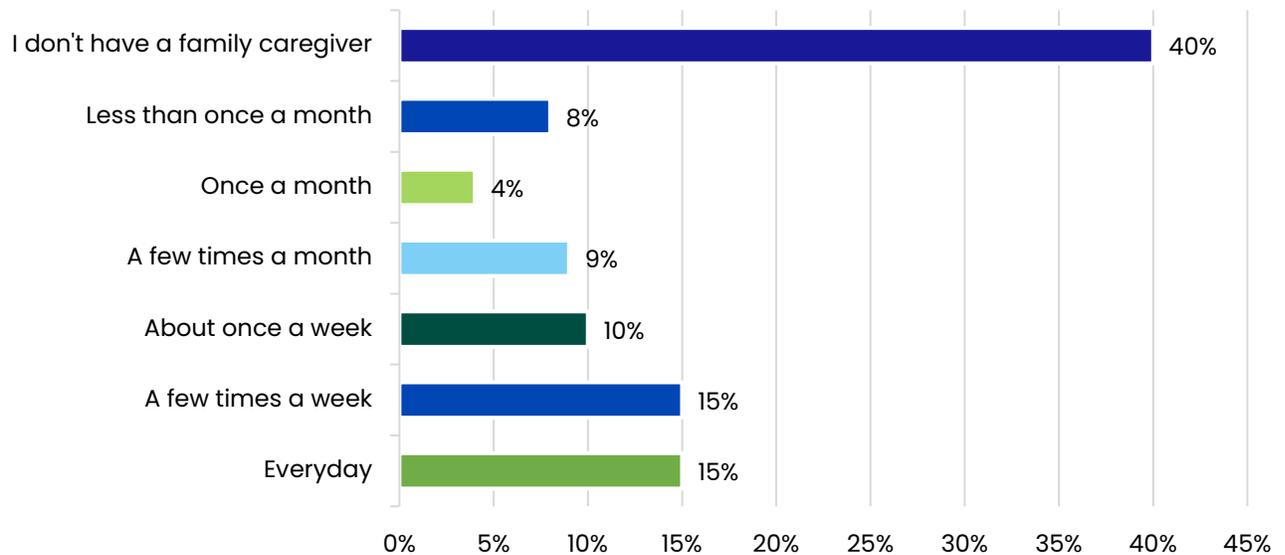
"The administrator here restricted my visitation with my daughter stating she is a problem in the facility."

FAMILY CAREGIVER

In addition to asking about visitation, residents were asked if they have a family caregiver who comes to help with their care needs. Fifteen percent of our respondents stated that they have a caregiver who comes every day to help them. Another 15% said they have someone who comes a few times a week. Ten percent said they have a caregiver about once a week. Nine percent answered that someone comes to help them a few times a month. Four percent stated that they have a caregiver about once a month. Eight percent noted they have a caregiver less than once a month. Importantly, 40% of all respondents answered that they do not have a family caregiver.

While some residents commented on how important it is that they have family that comes to help them, many residents noted that they live far away from their family and friends and don't have their support on a regular basis. This makes it all the more important that facilities give the best possible care regardless of whether there is a caregiver trying to keep the facility in line.

Do you have a family caregiver and how often?



Resident comments include:

"My granddaughter comes several times a week. Is very involved in my care."

"My son comes to visit and decorate for different holidays."

"Nobody is nearby."

"I have always been the family caregiver."

"They do or I would be neglected."

"If it were not for outside help, we would be in sad shape."

"My sister comes at least four days a week and brings me hot food to eat. She spends a lot of her money on food."

"A lack of confidence in monitored care has resulted in daily visits."

"No family members come – this is one of the major problems and it appears to be with others also."

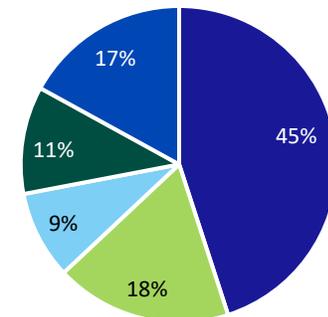
"My family visits. I hire an aide for one shift a day."

COMING AND GOING FROM THE FACILITY

When moving into long-term care, residents remain members of their community. We asked residents whether they can leave their facility to participate in community activities or to visit with friends and family whenever they choose.

We were interested in confirming that residents are able to come and go freely and wanted to understand what barriers prevent them from feeling like active members of their wider communities. Forty-five percent of respondents told us that they are always able to leave their facilities, and another 18% said that they usually are. Nine percent answered they are sometimes able to leave their facilities when they want to, but a concerning 28% said they rarely or never leave their facilities to participate in events or visit with friends and family when they want to.

Are you able to leave the facility for community events & to spend time with friends & family?

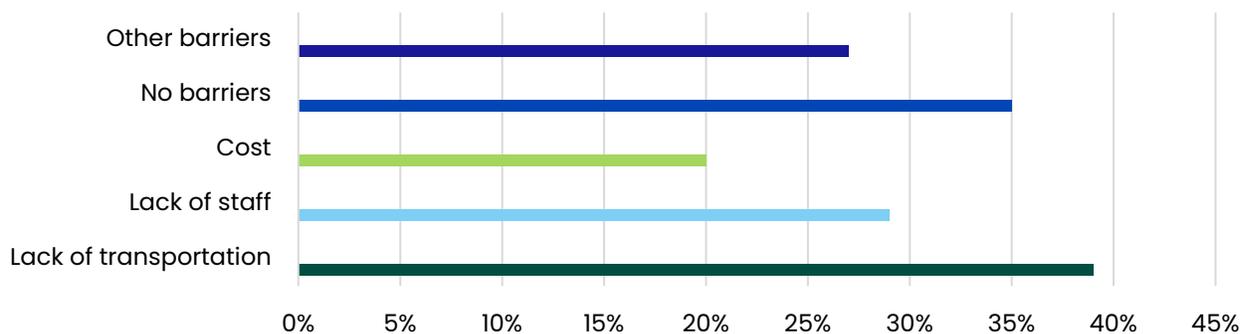


■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never

Residents who can go out when they want often talked about family facilitating their time away from the facility. A few residents talked about bus trips, dining out with friends, and community activities. However, many residents note they have not attempted this because of their disabilities or that their options are severely limited because of transportation and staffing issues.

When asked specifically about the barriers that prevent them from participating in community events, 39% cited a lack of transportation, 29% cited lack of staff, 20% cited cost, and 35% said there were no known barriers. Twenty-seven percent cited other barriers.

Are there barriers that prevent you from participating in community events





Resident comments include:

"Finding a ride is challenging."

"I don't think this is possible for me, because I require a lift to get in my wheelchair."

"If I do we have to rent a vehicle to get me there. Money, we don't have."

"My family has to schedule and pay a lot of money to get a wheelchair accessible van to take me out."

"Transportation is an issue. There is none."

"They tell me I need to have my own ride set up."

"Haven't even been offered the opportunity to participate in community activities."

"Not enough staff to lift me into chair and not staff available to transport us."

"There is no transportation for that."

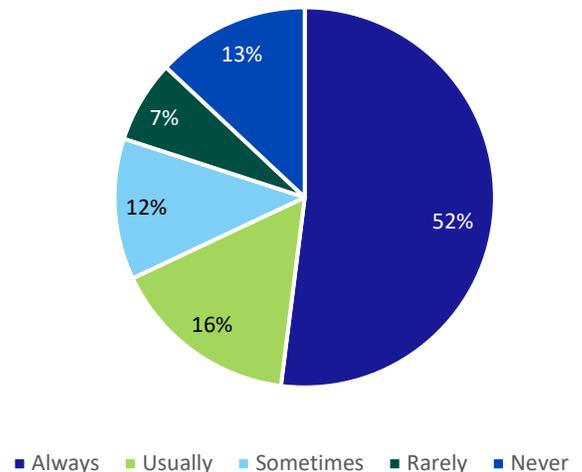
PARTICIPATION IN RELIGIOUS SERVICES

Religion plays a large role in many people's lives. That should not change when they move into a long-term care facility. Residents were asked about religious services and whether they can participate in the religious services of their choice, in person or virtually. We wanted to ascertain whether residents' preferences were honored and respected.

Sixty-eight percent of respondents answered that they always or usually can participate in the religious services of their choice, either in person or virtually. Twelve percent answered that they can only sometimes do this, and another 20% answered they rarely or never have access to the religious services of their choice.

Some residents complained that while some religious services are accessible, they are only for specific religions. Others noted they would love it if there was transportation to religious services. Some residents talked about the ways they make use of technology to access their religious services.

Are you able to participate in religious services of your choice, in person or virtually





Resident comments include:

"We have pastors but not from every denomination."

"I wish I could go to my church but there is no transportation."

"It is only offered in the facility twice a month."

"No Muslim clerics available."

"We don't have a Rabbi come here. They do a sabbath service on TV on Saturdays if someone remembers to put it on. However, other religions have Mass every single day. I would need to get on my laptop to see Jewish Holiday services."

"Only Christian services are offered."

"I Zoom my church service."

"My church broadcasts on YouTube."

"Sometimes they don't get me ready on time."

"Needs non-denominational... only offers Catholic."

MEMBERS OF THE COMMUNITY VISITING FACILITIES

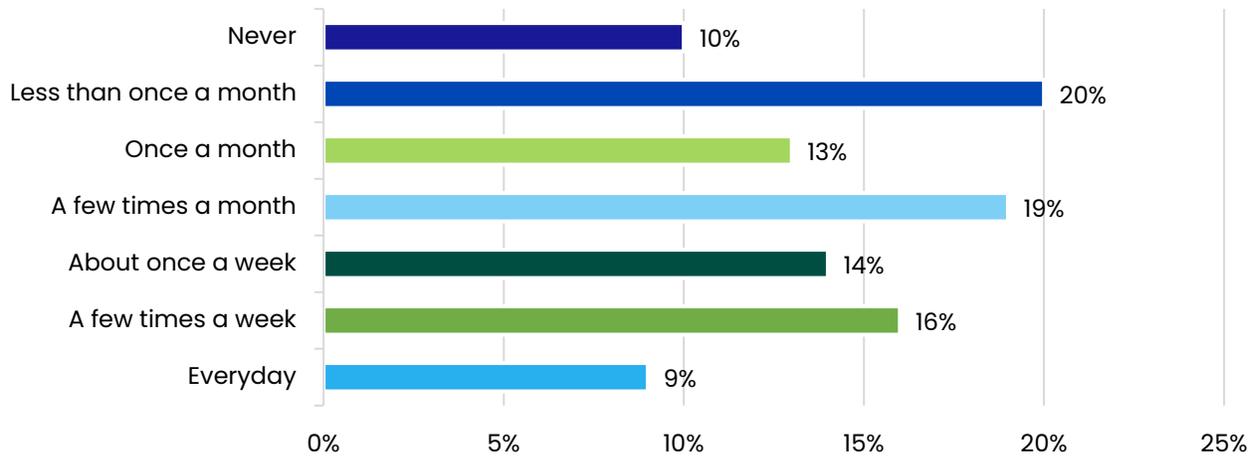
Long-term care facilities are often located in neighborhoods. Yet, members of the community often pass them by, never visiting unless they have a loved one living there. While several questions in the survey focused on how residents themselves stay active in their community, we also wanted to get a sense of whether the community engages with their facilities. We asked residents whether members of the community come to their facilities to participate in or host events.

Nine percent of respondents told us members of the community visit their facility every day. Another 16% answered that community members come a few times a week. Fourteen percent have members of the community come once a week. Nineteen percent answered that they have community members visit a few times a month. Thirteen percent have members of the community visit once a month. Nineteen percent answered that members of the community visit less than once a month and 10% said that they never have members of the community visit.

Residents shared that many don't see members of their community coming into their facilities, but they wish they would. Several residents noted that before COVID-19, their facilities had more community engagement, but it stopped during the pandemic and never recovered. The groups that used to visit no longer do. The residents who commented that members of the community do come said that most often these are visits by religious

groups and school children and again noted that they would like more involvement from the community.

Do members of the community come to your facility to participate in or host events?



Resident comments include:

"I wish there were more visitors."

"Was more before COVID-19, I miss it."

"They had a Valentine's party, singers and live entertainment."

"Not anymore."

"Sometimes during the holiday, but not very often does this take place."

"Usually church groups."

"I thank God for those people."

"Not as often as they used to."

"Love when the comfort dogs come in."

"Hosted events by community once or twice a year. Girl scouts, elementary schools come and read with us monthly."

"If members of the community have been here to participate, I have never seen them."

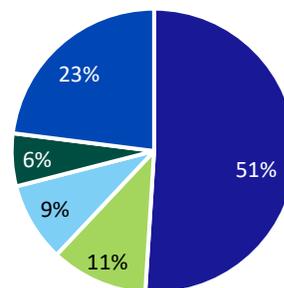
"I wish there was more community involvement."

TECHNOLOGY

As the generations that have grown accustomed to technology age, what people want, and expect, when they enter long-term care is changing. Many adults that are moving into long-term care have used the internet and smart phones for decades. We thought it was important to ask how accessible technology is in long-term care facilities for today's residents.

When asked whether they have access to technology, including smart phones, computers, tablets, or internet access, when they want to use it, 51% of respondents answered they always have access. Another 11% replied that they usually have access. Nine percent told us they only have access sometimes. Concerningly, almost one-third of residents, 29%, responded they rarely or never have access to technology in their facilities.

Do you have access to technology when you want it?

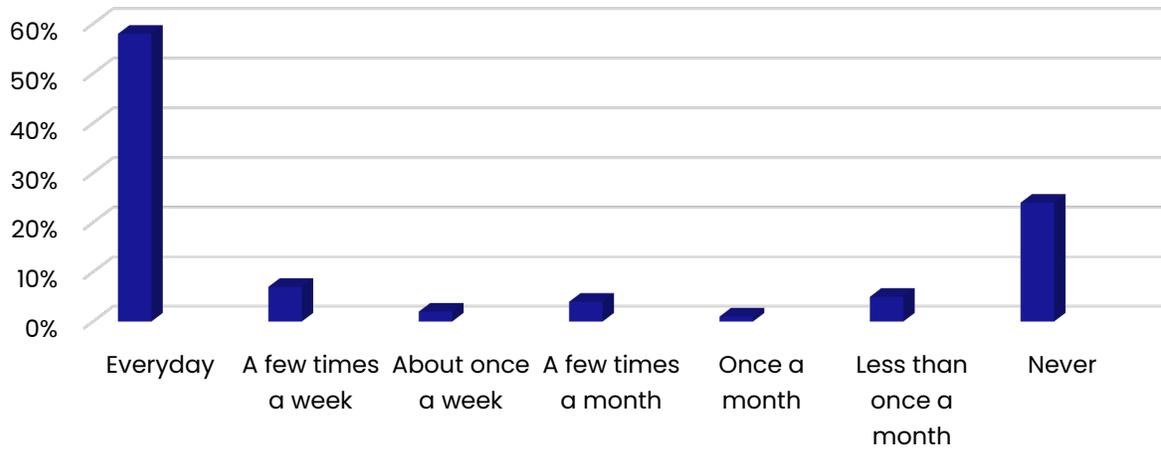


■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never

It is important to remember that the residents who answered this survey may reflect a population that is more likely to have access to technology because they responded to an online survey. While in some cases friends, family, or an Ombudsman program representative assisted residents in filling it out, the population that responded is still potentially more likely to have access to technology than the population at large. It is also important to note that in previous questions, residents referenced technology – both in terms of keeping them busy with activities on their phones and iPads, keeping in touch with loved ones via video, and attending regular religious services on YouTube or Facebook. Without access to technology, residents are more likely to feel isolated and less likely to have access to their rights or advocates who can ensure those rights are met.

We also asked respondents to share how often they use technology (smart phones, computers, tablets, internet access, Alexa or similar device) to stay in touch with family and friends. Fifty-eight percent of our respondents answered that they use technology to keep in touch with family and friends every day. On the opposite side of the spectrum, 24% said that they never use technology to keep in touch with family and friends. Another 19% of respondents' answers ranged from a few times a week to less than once a month.

How often do you use technology?



Resident comments include:

"Unless you have your own personal device, there is no access."

"Facility's computer has no Wi-Fi access."

"I have a computer but no internet."

"The facility does not offer internet to residents."

"I have and pay for my own access."

"Internet spotty sometimes."

"I have a lap top and a printer. Cannot use it due to no Wi-Fi."

"Wi-Fi has been down/unavailable for over two months."

"Must be provided by family."

"Building is not wired for internet. Residents must pay extra for services."

"Free phones, free Wi-Fi, and community computer desktops."

"No internet connections in rooms unless you subscribe to a paid service."

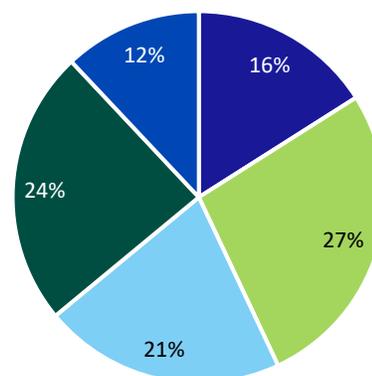
"My family advocated for an Alexa in my room."

STAFFING

Throughout our survey, residents referenced poor staffing as reasons why they experience other issues in their facilities. In their comments, they talked about low staffing impacts their quality of life in a variety of ways. We wanted to make sure we directly asked whether staffing is impacting them.

We asked whether there are enough staff in their facilities to meet their needs in a reasonable amount of time. Their answers were disappointing but not surprising. Only 16% of residents answered that they always have enough staff to meet their needs in a reasonable amount of time. This isn't whether their needs were met promptly or immediately, but in a time period that felt reasonable. Another 27% said their needs are usually met in a reasonable amount of time. Twenty-one percent said their needs are only met in a reasonable amount of time sometimes. Over 36% answered that their needs are rarely or never met in a reasonable amount of time.

Are there enough staff to meet your needs in a reasonable amount of time?



■ Always ■ Usually ■ Sometimes ■ Rarely ■ Never

It is hugely concerning that over one-third of all long-term care residents who responded to our survey rarely or never have their needs met in a reasonable amount of time. These needs can vary from small to large but include toileting, hygiene, and emergencies. Many residents are reliant on staff for almost everything.



Resident comments include:

"Always understaffed. They turn call bells off at nurse's station without ever coming into the room and checking on the resident."

"We are always short staffed."

"Too short staffed, agency staff don't come when assigned."

"Night and weekends are worse."

"Staff complain to me that they are working short."

"This place is always short-staffed. I'm only getting showers once a week."

"The call light has been left on for as long as three hours (usually it is on for at least 20-30 minutes)."

"Last night I waited from 6:30pm to 1:15am to be changed from soiled linens and chucks."

"This facility is a revolving door for staff and residents. Good employees are used up and burned out due to mismanagement."

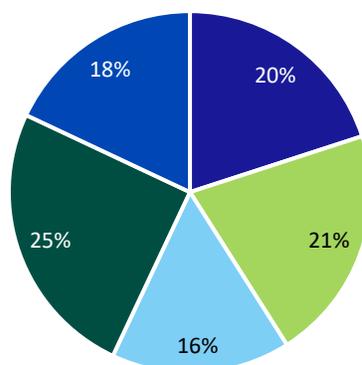
"Recent layoffs and constant turnover make the staff very unproductive."

LIVING ON YOUR OWN TERMS

Residents living in long-term care [are entitled to](#) person-centered care that allows them to live their lives the way they want, making decisions and feeling in control of their day-to-day and care. We asked residents to what extent they are living their lives on their own terms in their facilities.

Twenty percent answered that they feel in control of their life and decisions. Twenty-one percent told us that they have some freedom and control but there are limitations. Sixteen percent answered neutrally that they feel neither restricted nor fully free. Twenty-five percent told us that it is difficult to feel control over their life and decisions because of restrictions and constraints, and 18% answered that they feel heavily restricted and unable to live life on their own terms. Thus, while 20% feel in control, 80% feel limited or constricted to varying degrees and twenty percent feel highly restricted.

To what extent can you live life on your own terms at your facility?



■ Very easily ■ Somewhat easily ■ Neutral ■ Somewhat difficult ■ Very difficult



Resident comments include:

"They make me feel like I don't have any rights and make me feel that my thoughts don't matter."

"I continue to do what I enjoy."

"Because I'm completely at the mercy of others for help and timing."

"I have a half a room and a hallway – that's my experience here. It's the most restricted environment."

"Mobility restrictions, no one to transport me to activities."

"I have to advocate for myself consistently, but my skills are good enough I can live life as I want most of the time."

"Just within the rules of the facility, not like it was my own home."

"This is caused by my disease and lack of staff."

"This facility is an impediment."

"Limited freedom like going to bed and getting up when I want."

"It really bothers me that I cannot go outside."

"Facilities don't advertise your freedoms and some people are restrained from leaving on their own. I know my rights and tell the facility when I will be doing things."

RESIDENT RECOMMENDATIONS FOR IMPROVEMENTS

We concluded the survey by asking residents what can be done to improve their lives in long-term care. Their answers emphasize better staffing, better food, and more activities. They asked for empathy, compassion, and to have their preferences respected.

Staffing & Quality of Care

"More to do, better food, more staff."

"More staff/help."

"More staff, better food."

"Better staffing."

"Continuity of care. Better standards for staff. Supervisors on the floor at all times."

"Workers that will listen and be attentive to my daily needs."

"More medical and recreational staffing."

"Staff can be more attentive to resident's needs and not rush to provide care. Provide more assistance to social workers to address non-patient care needs."

"Higher staff, not use agency. Hold staff accountable for their behavior."

"More activities, keep to my schedule, need more staff and food needs to be better."

"More staff, improved communication, better food choices, employees with credentials to cook, state tested nursing caregivers."

"More staff, better food, empathy from caregivers. Staff that answers call bells."

"More staff per resident to help in a timelier fashion. More staff that love their jobs and make it fun to be here."

"More staff, more activities, more choices to spend time outdoors."

"Teeth cleaning services as well as periodic massage therapy."

"Better eye care."

"Get more staff in the building and cut down on staff turnover..."

"More medical and recreational staffing."

Food and Dining

"Prepare decent hot food; more staff; cleaner public areas."

"Increased staffing and better management of existing staff, higher quality food."

"Less noise, more worship, better food."

"Freedom to choose what we have on our meal menus. As of now we have none."

"Better food, better staff."

"Better food, transportation, and understaffed especially at nights."

"I would like better qualified chefs who know how to cook American food that is tasty."

"A caring management. Better food..."

"Improved food, improved activities, more aides so we can get showered more than once a week."

"More stimulation. Better food and better food services. More opportunity to mingle with more of the residents..."

"Improve the quality of food and staff."

"More staff, improved communication, better food choices..."

"Nutritious food."

"Freedom to choose what we have on our meal menus. As of now we have none."

Activities, Engagement, & Quality of Life

"Interact more with others who stay here in the facility."

"More things to do, I get so bored."

"More exercise, weight machines"

"Maybe sit in a pool. Get some sun. Sit on the bench outside. Go on a few trips."

"Get more activities."

"Let us smoke cigarettes."

"More transportation to go into the community."

"Get more involved in activities."

"Daytrips for educational purposes, aquarium visits, planetarium trips."

"More outings, I want to go out."

"I would like to see activities that interest me. There are rarely any activities held outdoors."

"More stimulation. Better food and better food services. More opportunity to mingle with more of the residents..."

"Have more staff willing to help or find help to get activities and other informative events in the facility."

Environment

"Cleaner public areas."

"Less noise, more worship, better food."

"Lower buttons and make door framers wider, revisit doors to vestibule to elevator."

"Remove all the plastic floors and furniture. Replace with the carpet and comfortable furniture that was here when I moved in."

"This facility needs a happier environment."

"I like peace to live and do what is best for me."

Management and Oversight

"Get better managers."

"Close them down and start over. Pay attention to what is going on. Pass legislation..."

"A caring management. Better food. The healthcare services and nurse included in my contract."

"Listen to residents and make necessary changes when needed."

"Management oversight. Properly trained and adequate staffing levels."

CONCLUSION

Throughout the survey, the one thing that became clear in resident responses is that, even in the best cases, most residents did not view their facilities as their home. The residents who talked about having a better quality of life talked about adjusting and adapting to the facility's schedule, rather than the facility adjusting and adapting to theirs.

Many residents who gave more positive answers talked about having more freedom because their family members came and assisted them in their understaffed facilities or discussed the fact that they knew their rights and were able to advocate for themselves.

Several answers throughout the survey indicated a lack of autonomy. Residents indicated that their facilities were understaffed to the point that their daily routines and quality of life suffered.

Many of the comments illustrated that they want their rights respected, their care and needs met in a timely and appropriate manner, and they want to be treated with the same dignity and respect as everyone else. Although some residents reported positive experiences, the majority still face significant challenges.

Action Steps to Improve Resident Care and Experience

To support residents in obtaining quality care and experiencing quality of life, we recommend the following:

-  Use the findings to push for improved staffing levels, stronger resident rights protections, and more person-centered care practices at the local, state, and federal levels.
-  Share the report with policymakers, facility administrators, Ombudsman programs, family councils, and community organizations to raise awareness about resident experiences and systemic issues.
-  Use the insights to help residents and family members better understand their rights, identify concerns, and advocate for changes within their own facilities.
-  Incorporate the findings into staff training, quality improvement initiatives, and resident-centered care planning to ensure facilities are responsive to residents' needs and preferences.
-  Use the themes to shape future surveys, studies, or listening sessions to continue tracking resident experiences and measure progress.



ⁱ Some pie charts do not add up to 100% because some percentages were rounded up or down.