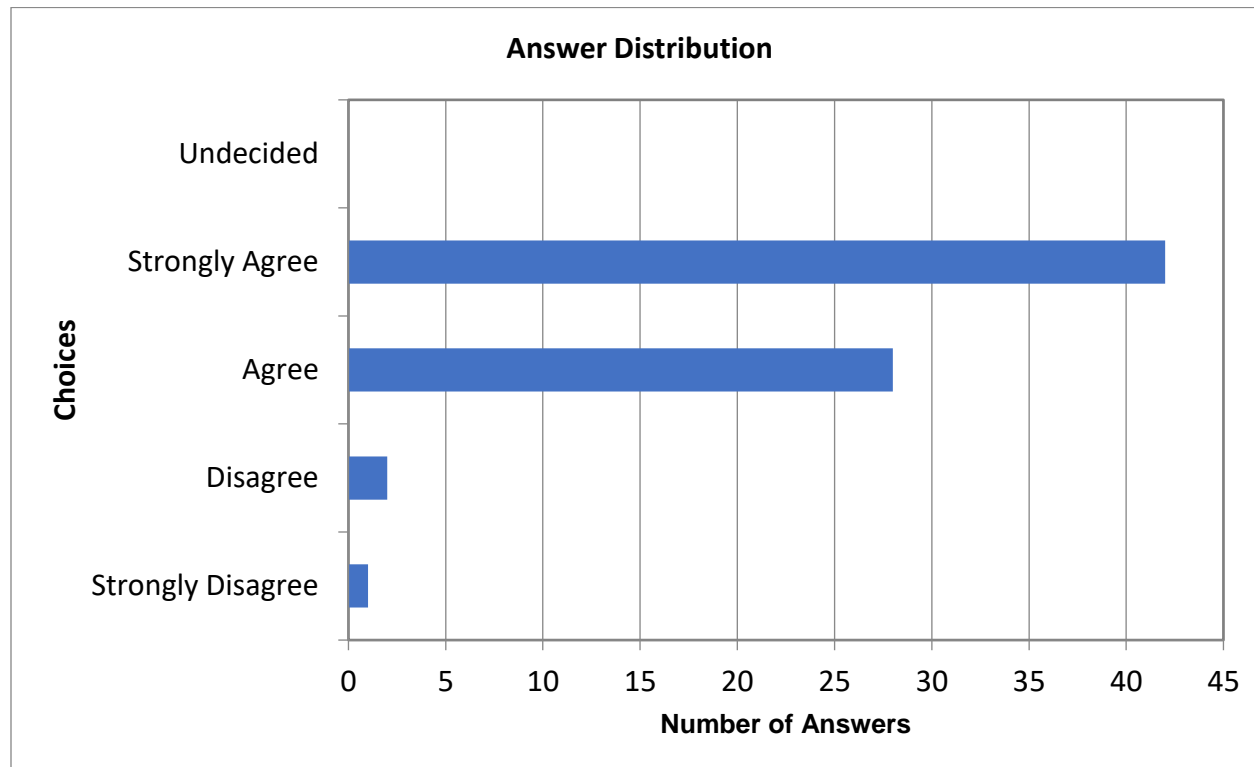




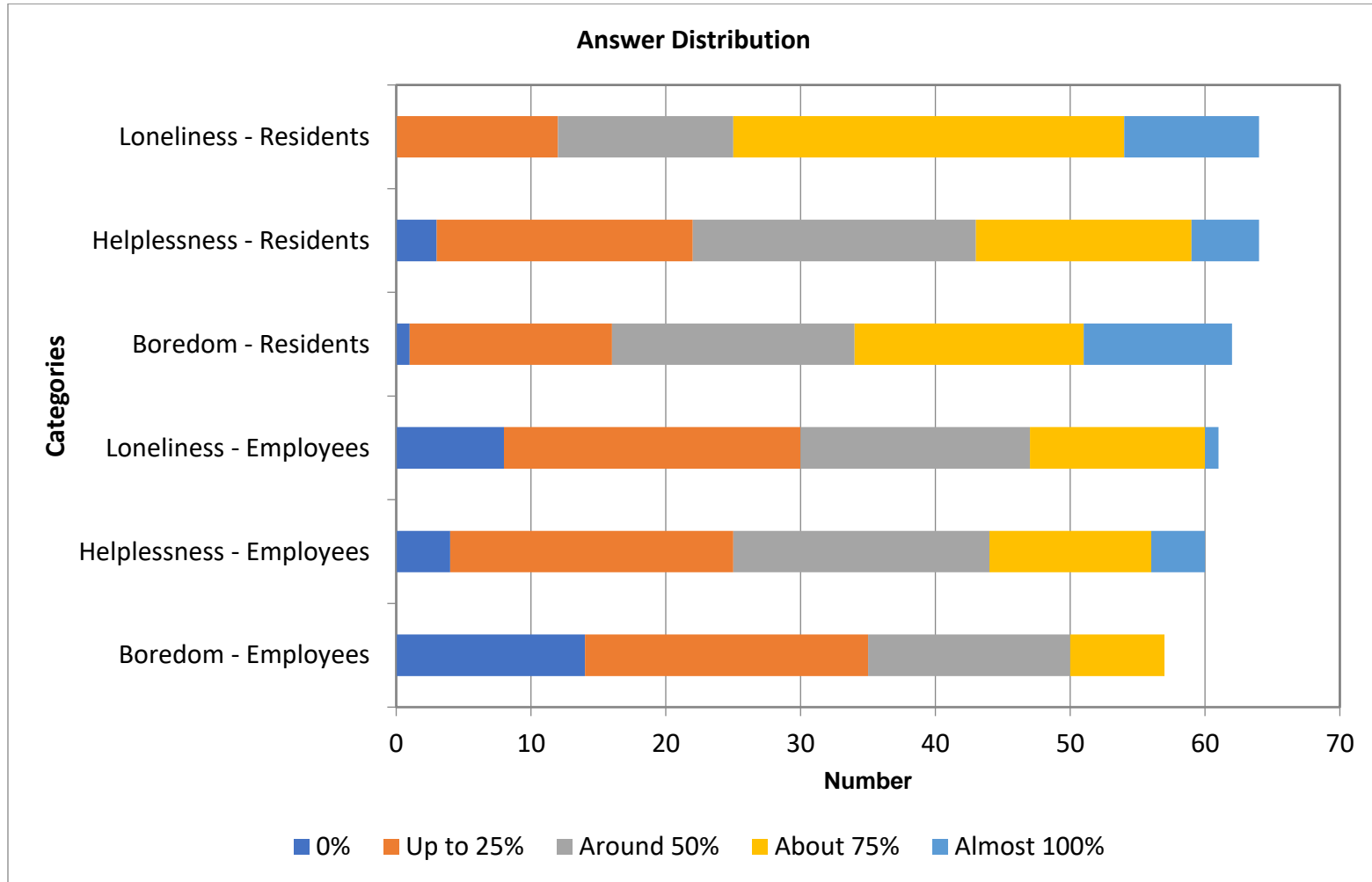
Registry Member Insights from the 2020 Pandemic

A survey opportunity was sent out to Eden Registry Members in mid-December 2020. The survey remained open until mid-February 2021. A huge thank you to the 73 Registry Members that responded. This is a summary of their responses.

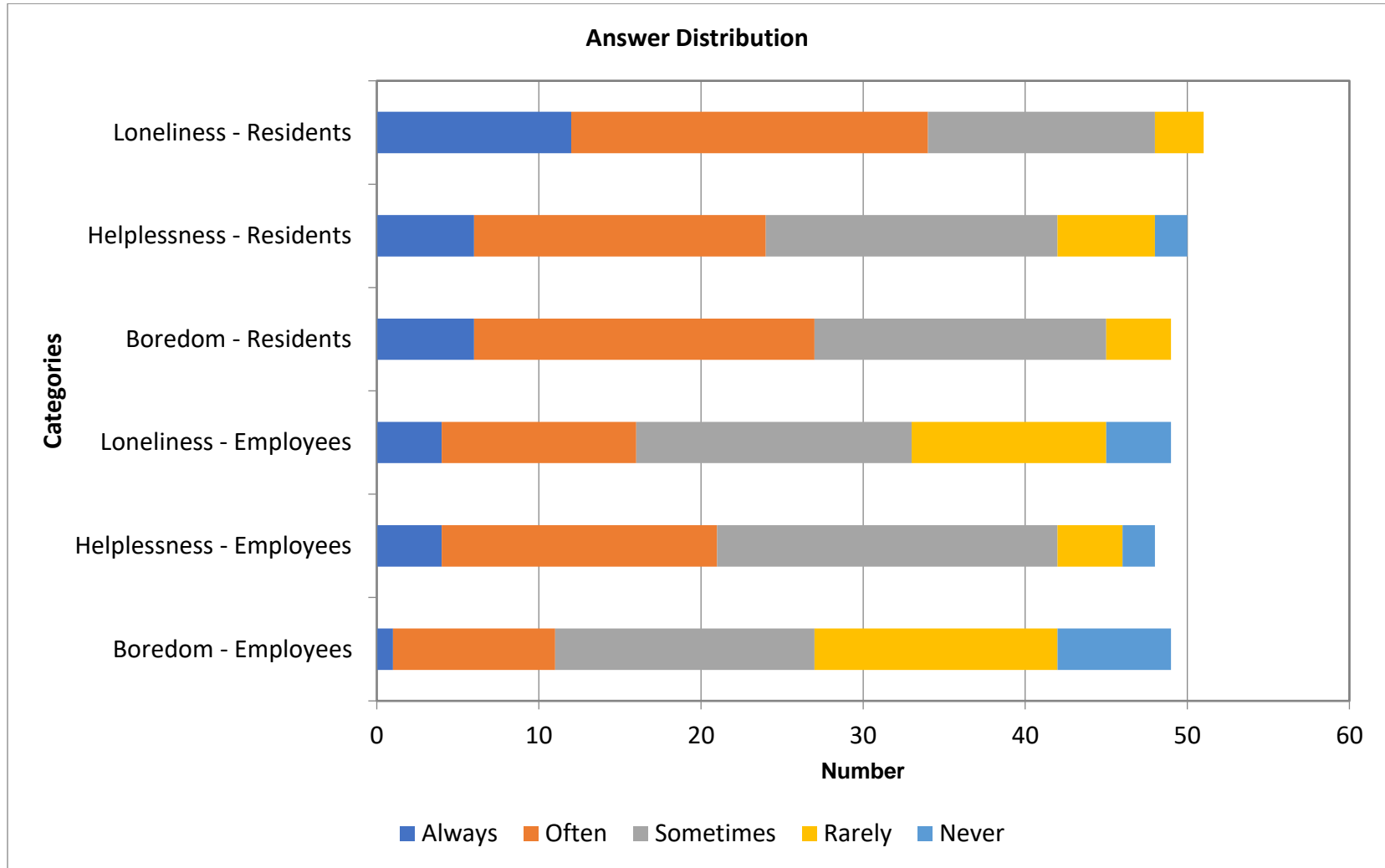
We are seeing an increase in loneliness, helplessness and boredom in the lives of the residents we serve.



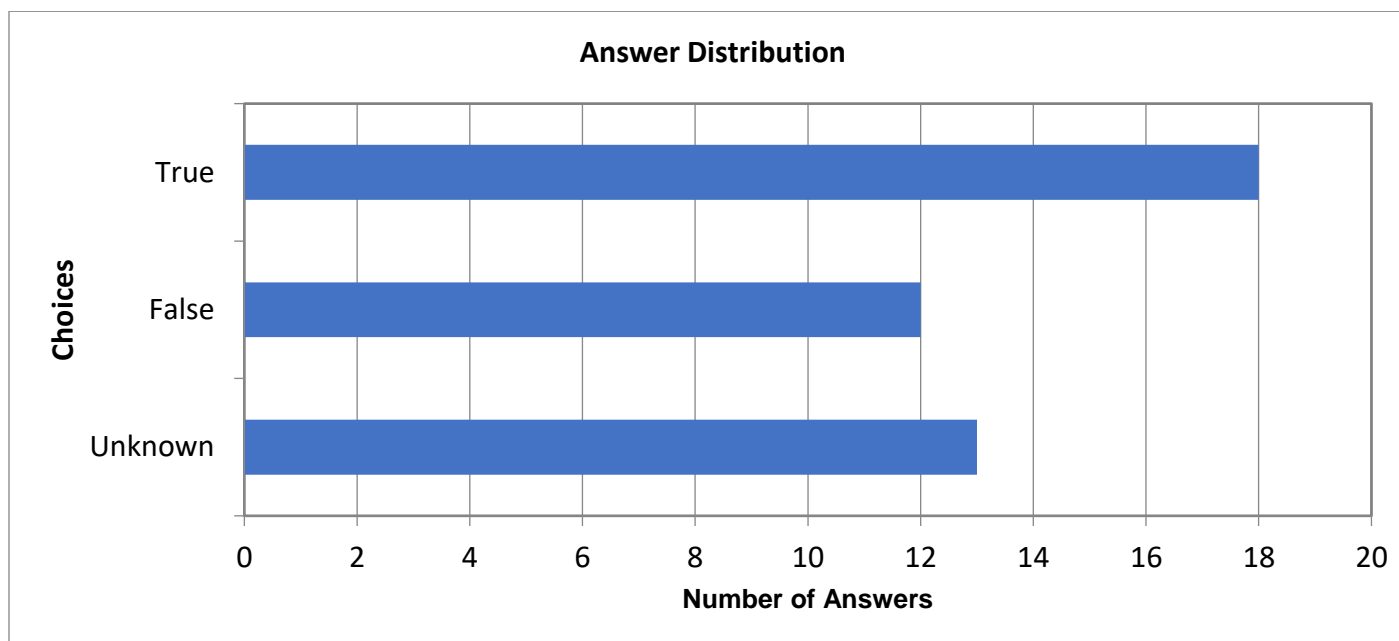
Rate the Three Plagues based on the percentage of residents/employees that are experiencing them.



We are seeing the plagues have a negative impact on the health and well-being of the residents/employees:



We have seen residents die from loneliness, helplessness and/or boredom during the pandemic.



What lessons have you learned about companionship (the antidote to loneliness)?

- Connection is essential for overall well-being.
- Little things matter; window visits/virtual visits are vital; communication with families needs to increase since they cannot be here.
- It is crucial that you visit every resident in some way daily even if it is just talking through a quarantine door. Letting them see you and hear you helps tremendously.
- Now more than ever we need to nurture our relationships with our elders. We are their family more than ever before.
- We have learned that our neighbors (residents) were suffering like many of us. Video chats, window visits, and phone calls have helped with this for family and the neighbors. The COVID pandemic made our home

institutional in some ways. Wearing masks has made it difficult for our elders to smile at each other and for us to show a kind face in all this chaos.

- Companionship brings happiness, contentment, and peace.
- Everyone has a need to feel needed and appreciated.
- it is essential, however have also seen residents embrace virtual visits when assisted by staff.
- Companionship is vital to overall health and well-being.
- We need the physical touch such as a hug, handshake, pat on the back.
- Residents need something to look forward to such as a visit from that family member or a friend. It helped them to keep track of what day and time it is.
- People will seek companionship in many ways when they don't have much to choose from. Behaviors or unmet needs pop up.
- We have learned that the importance of developing meaningful relationships between care partners and others has grown in the absence of normal social contact.
- Human touch and companionship are absolutely critical to our elders thriving and surviving.
- We have seen that the absence of the companionship of the residents' families, volunteers, church groups, friends, etc., has impacted our residents greatly. Our more alert and oriented residents understand the impact COVID is having on the world and can understand the restrictions. Our more confused residents unfortunately are just more lonely and don't understand why things are different. They miss interacting with others and going to activities. Loneliness has been harder in many ways than COVID itself.
- I have learned that people have found ways to make connections and build new relationships where other access to other relationships have been reduced. People tend to naturally work in the level of companionship they need, but the people and/or animals who fill that need may change. I find this to be true with both residents and employees.
- We cannot be everything to everyone. Loosing families and needing to be the companion and care giver for our Elders has highlighted that we are NOT funded to be able to have the time to do this. It is very hurtful to have to make a choice between letting go of the hand of a lonely crying elder to ensure you can help another use the bathroom. These are not choices that should not have to be made. We should be supported with the resources to be able to help all.
- That loneliness can and does strike even when you are surrounded by 100's of people.

- Building relationships with residents and coworkers helps reduce the feelings of loneliness as we help them find ways to stay in contact with their own families.
- We can't take for granted our daily relationships and interactions with others. This pandemic has shined a light on how very important these are. We must be creative in keeping up our meaningful relationships....Always!!
- There is a definite difference between friendliness and companionship.
- The lesson we've learned through the pandemic is that companionship is very important. Without it we see an increase in loneliness.
- We are seeing there is a true difference between friendliness and friendship and when elders lose contact with those they are in true relationship with they decline. It is so important the caregivers move from tasks to relationship.
- The moment of time you choose to give to someone else is priceless. Something small to you may mean the world to them. Relationship is even more valuable during the pandemic as staff more than ever before have become family.
- It is very difficult to substitute family companionship.
- It doesn't always have to be a family member's touch. Everyone needs someone and human contact daily.
- It is hard to hug with full PPE.
- Even during a pandemic, it's up to all care partners to stay connected to all we serve and meet the needs of those we serve, pandemic or not. Our journey will have ups and downs, many challenges will arise, but we won't give up, life goes on!!
- The importance of a true companion or loving family member verses the relationship of a paid care partner. We can provide close and continuing relationships for our residents but there is nothing like the love from a family member that eases loneliness.
- It is necessary to sustain life.
- That it is very difficult to take the place of close friends and family when companionship is concerned. We need to be well known even more when the normal visitation is suspended.
- How important it is for everyone's well-being. Sometimes you forget in the busy times of the world but then you realize the importance.
- Companionship - the feeling of belonging and having a "person" I believe is key. The world is a lonely place if you do not have someone to share it with. Having someone to make the good days better and bad days

bearable makes this journey all worth it. I always try to find a connection to everyone for this reason. An interest, family, something that makes them feel like they have a reason to come to work or get up in the morning because someone would miss them otherwise.

What lessons have you learned about balancing the giving and receiving of care (the antidote to helplessness)?

- Making yourself a priority to receive care.
- The importance of communication.
- The neighbors taught us that we could get through this. They showed patience and if they were willing to stay in and not have visitors we could too. We have remained COVID free in our home through this pandemic!!
- Caring for each other emotionally is a blessing to both.
- Everyone likes to feel useful and doesn't like to feel a burden to anyone.
- It is not hard to provide the physical care but the personalization of it is impacted by the masks, PPE etc.
- The pandemic has been hard on all staff. It has been important for staff to give care to each other.
- I feel that staff felt helpless in the fact that they did not know how to help the elders-frustration of all changes that took place-
- In the dining area you used to see residents helping residents, such as a resident getting a cup of coffee for another or a snack.
- Volunteers need the feeling of giving back and helping just as much as the staff/residents.
- People want to give and receive. If they don't get either one, it really starts to hurt staff and residents.
- Providing opportunities for the Elders to help others and the care partners is more important than before.
- While it is critical for both residents and employees, it has been difficult to maintain focus.
- Our residents are mostly isolated in their rooms and miss being a part of the action. They miss being able to participate in day-to-day activities. They also feel helpless that this has gone on for so long.
- I have learned that the people in this Home (and we are likely not alone in this) have had the ability to adjust and adapt in ways that I would not have thought we would/could. We are resilient! We have become a more connected team and community and the residents are giving care to the people, plants and animals who need it, as much as they are receiving it.

- Our staff have felt more helpless I believe than our elders as they have often had to make difficult choices that leave an elder unsupported. When the staff have compassion fatigue, they feel helpless and job satisfaction has gone down. We've also seen/heard this from our volunteers, that they want to do something for us but they simply cannot. Even in management, there comes a time when a boundary needs to be set in order to continue on. This makes many feel like failures and like we are helpless to do what is needed.
- With short staffing because of positive test results with staff, time is of the essence and many times there is not time for balancing care. Very frustrating!
- Giving and receiving helps one feel needed and have a sense of purpose. Residents have learned how to give encouraging words to co-workers who maybe having a difficult day and staff in turn meet resident needs.
- We have to remember to take time for ourselves and accept help when it's offered. Healthcare workers often forget to care for themselves, as they are always focused on giving to, and helping others. This is a difficult balance, especially during times of crisis, but it is a must!
- Opportunities to give care, self-care included, helps with those feelings of helplessness especially during this pandemic time. It helps with boredom as well.
- The pandemic didn't really make an impact on the giving and receiving of care.
- This has always been hard for us to accomplish, but we are seeing more elders help each other as they have compassion for each other.
- Everyone is going through the pandemic, is touched by it in different ways and everyone has something to offer. We have realized that we have to take moments to allow our elders to share and give back. Many of them compare this experience to something in their past which provides encouragement that this too shall pass.
- Isolation makes it difficult to balance giving and receiving.
- Residents get weaker without human contact, depression sets in everywhere.
- More important now than ever.
- Continue to offer choices, be creative. We all want meaning in our lives and doing for others brings joy and can eliminate helplessness.
- Residents have been receiving more care than they can give due to all the restrictions around the pandemic. We needed to learn to be more creative when alleviating this plague.
- When families and friends are out of the picture it puts a larger burden on the care partners and stretches time allocations to the limit!

- Personal needs are just as important as practical needs. The residents need staff now more than ever as they do not have families to touch, see, etc. everyday.
- This is a hard lesson.
- Being able to accept help, care, etc., from someone else is hard for some, myself included, but I think of the warm feeling I get from helping someone and remember I can't do it all myself as well as how can I look after anyone else if I have nothing else to give. To provide the opportunity for someone to "do something" themselves, maintains their care level, sense of pride and who they are.

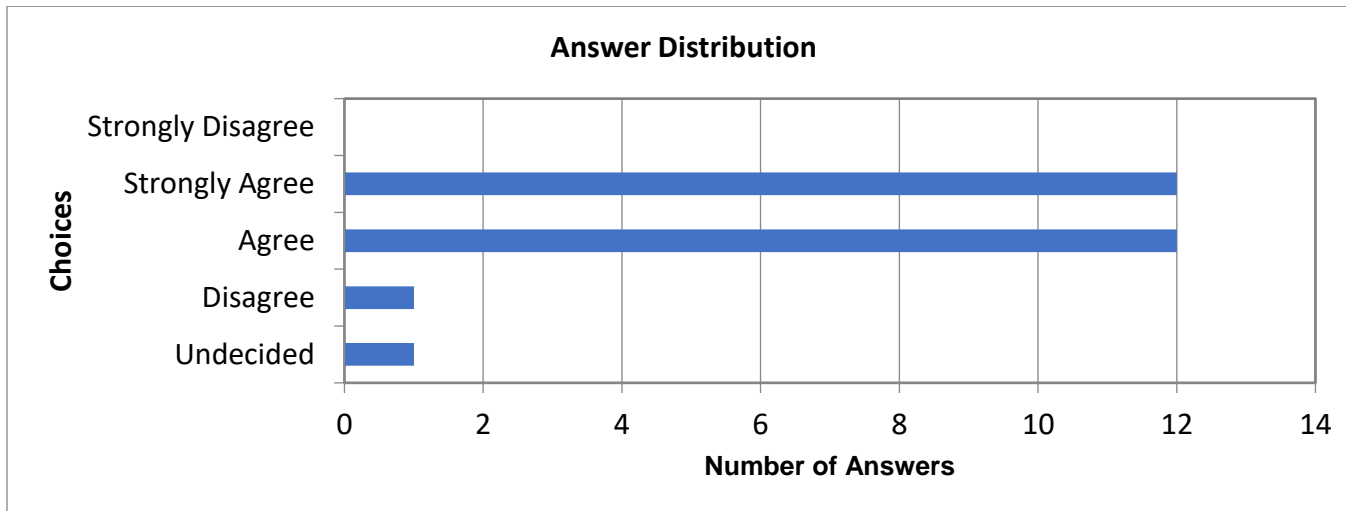
What lessons have you learned about variety and spontaneity (the antidote to boredom)?

- Cross-training is vital to ensure variety and spontaneity is still happening for our residents. In our pandemic plan, our recreation staff were pulled from recreation to clean centre core areas. This left house staff responsible for implementing a variety of programs.
- Not be afraid.
- We have learned the neighbors love BINGO and found ways to have this frequently. As our neighborhoods opened up, we started to do different events in the home. Prior to this, 1:1 visits were important along with video chats with family members.
- Change in routine can be fun and exciting at times offering a new joy for the day.
- Variety and spontaneity provide a break in the day and gives purpose.
- It is very important.
- We learned to adjust and think differently. We learned it is hard to make sure everyone, when isolated to rooms, gets the attention they need. We are lucky to have a broadcast station and were able to continue activities via broadcast station such as bingo (using paper bingo cards), trivia, guess the song, traveling and more.
- It's tough to just have the ability to give tangible items. They don't replace the spontaneous fun or variety of life that a multitude of people bring.
- We have learned that Elders are not necessarily missing the large activities like we thought they would and have worked to increase opportunities for variety and spontaneity instead.
- Spontaneity is very important.

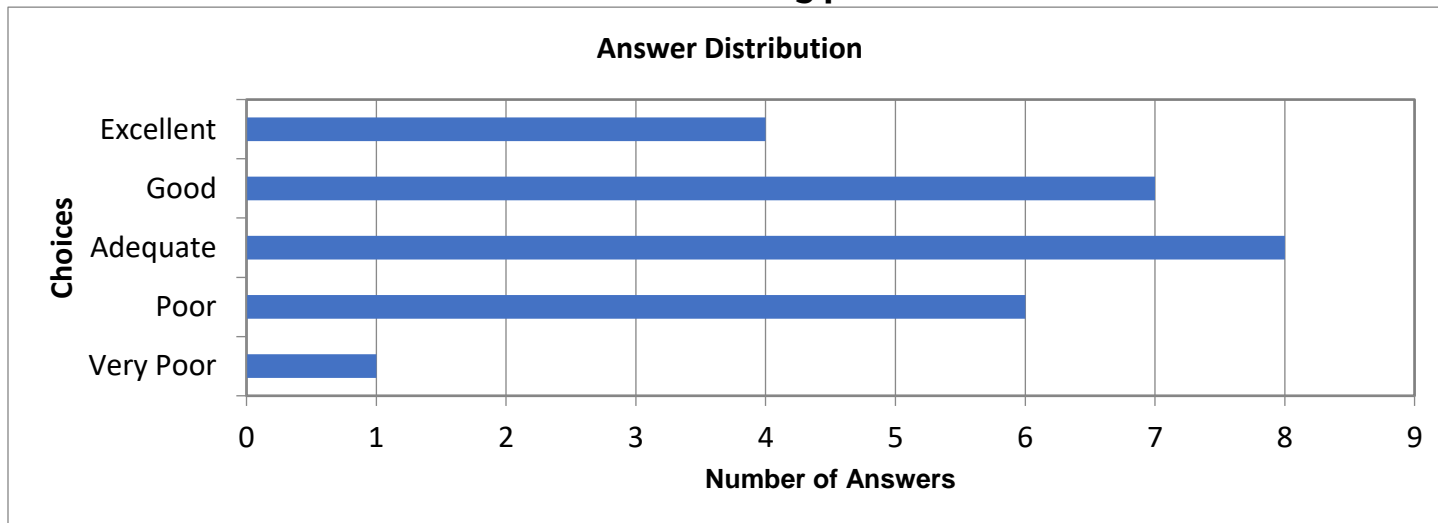
- We have all learned just how important spontaneity and activities is to the well-being of our residents. Our Community was so lively and happy and now it is very sad. It is very hard to provide that kind of variety when the residents are isolated in their rooms.
- I think that overall the idea of what we have considered when thinking about variety and spontaneity has shifted. With limited access to the outside world, and a whole lot of change, we have had to get creative and shift our thinking and prioritize in ways we hadn't ever thought we would need to. This has been a time of transformation and it started out very hard, but with it has come growth.
- Luckily, we have 6 cats that live with us, so we have been able to continue to see variety and spontaneity. It is much less than it once was though. We learned that planning spontaneity is impossible, and the most important thing is to leave opportunity for it. One day, we had tons of balloons around and we just popped them into each neighborhood without saying anything and it was so lovely to watch the smiles and activities organically happen. It doesn't take much, but when it works, it's magic.
- That the littlest of things can break the boredom and bring Joy!
- Residents love this much better. There has been greater participation in activities that are 1:1 or in very small groups. Residents who normally decline any type of activity have been participating.
- It is so important to get creative, and really break out of the norms...really think outside the box. It can be something very simple, like making colorful, and inspirational posters to add color and fun to your environment. You need a variety of things like this.
- Creating and nurturing a culture of lightheartedness and fun, remembering that we still celebrate life even though it looks different. This has nothing to do with what might be scheduled on the social/activity calendar.
- With COVID it is harder to be spontaneous as we have to think of safety first, social distancing etc...
- Well, we have thrived here. We have learned that small groups are better for relationships and the staff are not bored because this is a lot of extra work. They don't need constant activities. We are learning they are needing companionship to fight boredom. We are implementing a visiting volunteer program for when we open back up.
- Take time to laugh and smile with your eyes (with mask they can no longer see our smile, but they say than can tell by looking at our eyes)! Our staff have planned themed days twice per week just to allow staff to dress up and make the residents smile.

- It's hard to get residents involved in rooms as they prefer to be out of rooms. While in rooms they just want to sleep.
- Laughter is the key.
- You can still achieve this in tough situations, even though it is challenging.
- There have been many challenges to engage in the things we once did so freely. Doing things in a different way is okay and being creative in all you offer is huge!!
- How important it really is, and how it can make such a difference in our days.
- That the smallest happenings can be turned into huge boredom busters!
- Small pop-up activities, even on individual levels are appreciated at this time.
- It doesn't have to be big and wonderful. Sometimes time spent is the best thing. This past year we added another Care partner to our daily compliment, just for this reason. Their role was very open. They had a list of suggestions from our life enrichment care partners of what activities the Residents on each neighborhood liked. The care partner floated within the neighborhood visiting and asking the Resident what they wanted to do if anything, Being totally aware we would never replace their family or things they were missing but giving them the opportunity to use their voice to share their experience or try something new. Some days this care partner went from room to room with an ipad to Facetime families or make calls so they still felt connected. We didn't see an increase in responsive behaviours or care demands as expected. Days were filled with activities and conversations that would have not happened without this extra role. This has definitely set the bar of where we want to be and how do we make these moments happen every day not just during a pandemic.

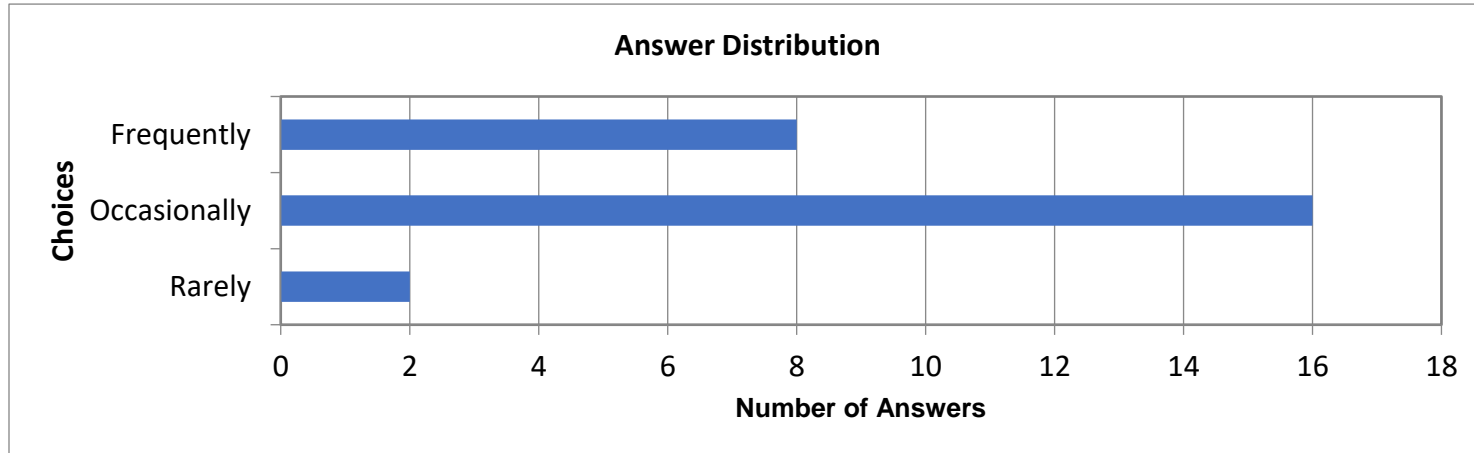
Our efforts to implement person-directed care prior to the pandemic have helped us do better during this time.



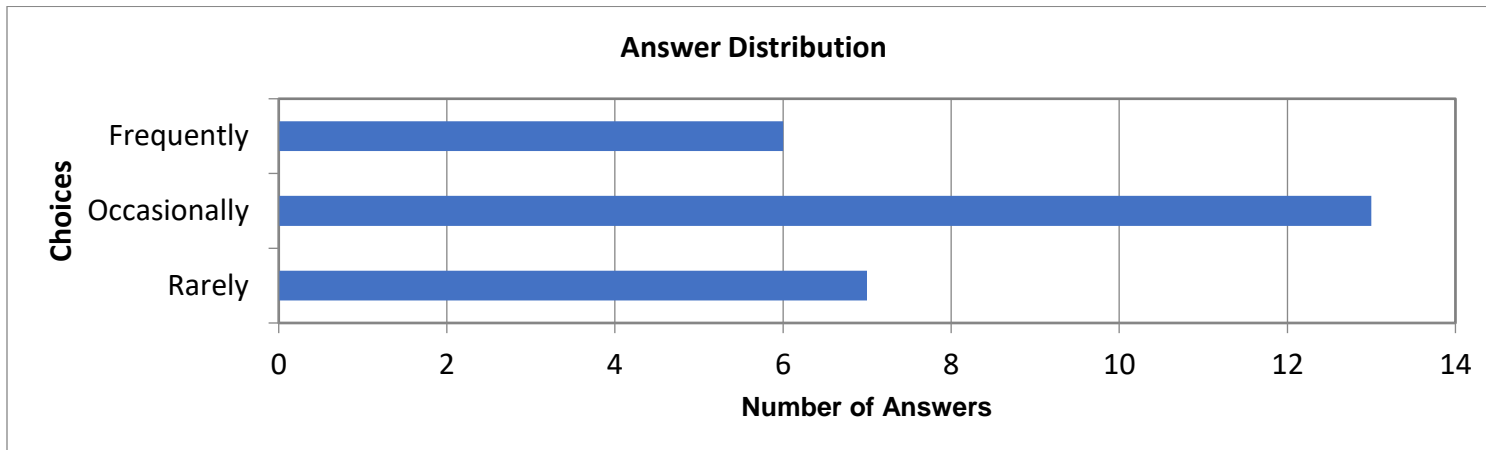
How would you rate your ability to include those most impacted by decisions made during the pandemic, in the decision-making process?



How often did you use the Eden Alternative Principles and Domains of Well-Being to aid in problem solving and decision-making before the pandemic?



How often did you use the Eden Alternative Principles and Domains of Well-Being to aid in problem solving and decision-making during the pandemic?



What person-directed care changes have you been able to sustain despite the pandemic?

- Our person-directed care was sustained throughout the pandemic.
- We were able to keep autonomy for when the neighbors wanted to get up and go to bed. They picked the events of the home they would like to do, picking out clothes.
- Care partners dining together.
- The resident's ability to direct their care.
- Same staff.
- Take-out food, door dash, online shopping and deliveries.
- We have been able to sustain our learning circles, huddles, and Elder of the Day methods throughout the pandemic. Our Care Plan Stories continue to be updated and utilized as much as before.
- Continuing with meaningful activities and virtual visits.
- It has been very difficult to sustain person-directed care during this pandemic. We can't allow the residents to choose their way when we have to consider their safety. The regulations and restrictions by our governing bodies have dictated what we are to do. We have tried to keep their preferences in mind in every way that we can like with food, clothing, times to get up and times to go to bed. We have provided snacks and as many safe activities as we can. When you are in the middle of an outbreak however all bets are off. People are moved from their homes and placed into other rooms, it is all very heartbreaking and yet mandated.
- We continue to offer choice at every opportunity. Autonomy has always been something we honor, and we have continued to do so. In fact, at times without families, this has become easier because we can allow the person, as who they are today, make choices, instead of the families saying 'mom would never want to be seen without a bra' at 89 and with dementia.' She really doesn't want to wear it and now she doesn't have to without someone being upset.
- Food choices, making mealtime a highlight! Creating individual preferences around bathing and personal care.
- Resident choices and decision making
- Keeping up with resident choices, and requests. Giving the best dining experience possible. Encouragement and appreciation of our residents giving back to us/others.
- Consistent staffing, daily. Neighbourhood Circles. Elders making decisions about some day-to-day choices that impact them as much as possible. Social time, even though with smaller groups.

- Residents were still given choices regarding their care.
- Resident choices.
- Person-to-person relationship with resident. More 1-to-1 visits.
- A lot of it.
- Using identity to provide the best care and well-being for those we serve.

What additional/new person-directed care changes have you implemented during the pandemic?

- Electronic communication with friends and family.
- We have implemented creative ways to connect residents to their families and friends.
- The absence of large-scale activities has forced our team to focus on individual pursuits for the Elders, which has allowed us to know them better than ever before.
- Virtual visits and entertainment.
- Trying to grant any small wishes that we can. We have also really counted on their Care Givers to be their lifelines.
- Introduced the Angel assignment to management to daily check on needs and desires. Work together to problem solve and create meaning, connectedness and security!
- Personalized activity programming rather than group.
- Including ALL staff (administrative, maintenance, etc.) in direct/frontline care, to assist in meeting all resident needs.
- Teaching and assisting families and residents with Zoom, Google, and other technologies, to help assist in face-time visits, while following all safety guidelines.
- Blended staff roles. Everyone did everything (within their scope of practice).
- We implemented zoom calls with loved ones.
- Games on halls, more room-to-room visits.
- Preferred virtual visitation.
- More patience, being in the moment.

While living through this pandemic, what lessons have you learned about the Eden Alternative journey?

- As our province lifts restrictions for long-term care homes, it has been very challenging to lift them in our own home due to the unknown. We need to constantly remind ourselves this is our residents' home, they need to be involved in the process and the risk and benefit of everything needs to be accounted for so decisions are not made out of fear to enable our residents to have quality of life.
- I found it difficult to keep out the "institutional dragon" because as a leader my focus was also on the ever-changing guidance for COVID. We were also going through a remodel during the pandemic and the neighbors and care partners were moved throughout the building and the sense of neighborhood wasn't the same.
- Loving and providing companionship with family atmosphere offers freedom of expression and much joy with contentment.
- The Eden Alternative is a journey and not a destination.
- We need to use it as we continue the journey. Making the decisions during Covid, it was hard to involve residents due to isolation to rooms at times, staff not going neighborhood to neighborhood, and the guidelines to keep everyone safe. In the process the goal is to keep everyone safe and trying to keep residents first.
- It takes leadership to embrace Eden, and for the rest of the team to implement.
- That even though there may be setbacks along the way, we are always growing in some manner and will never stop the journey.
- Human touch and meaningful purpose are very important.
- Applying what we have learned through the Eden Journey will be absolutely necessary to help our residents recover and start living again after this pandemic is under control. I believe it will be embraced and implemented much more by our Care Givers because they can see the sad effects of the 3 plagues.
- When safety is the top priority, almost all other domains suffer for it. Safety is important and has been paramount however, living with it as the MOST important does NOT equal a life of abundance. We never asked any elders what their choice would be about not seeing families and the risk of the COVID. It wasn't their choice and it was evident that they would have chosen differently.
- I can't imagine navigating the pandemic without the tools of Eden at our side!
- That it takes a village to take care of one another.

- As always, the Eden Philosophies are very relevant! No matter how hard times get it is imperative we keep our persistent patience, hope, courage, and strength up. We must remember, we may have setbacks, but things WILL get better. :)
- It's the only way to go. We were SO much better off than our institutional neighbours. Our Elders were more content, their families trusted us because of our emphasis on relationships and customer service BEFORE the pandemic. It's been truly remarkable. Plus, once you are on the journey you stay on it. Nothing destroys that, even a nightmare challenge like this.
- We learned that we can still follow the Eden Alternative through a pandemic and adapt.
- The Federal and State regulations have dampened our journey. They are far from patient centered, focused entirely on safety, and fail to recognize that isolation and loneliness are also killers.
- What a great tool to have!! Kept me grounded and I used many tools from our learnings and teachings.