

## Transcript

Matters of Engagement podcast

Episode: "Beyond Mandates: The Essential Input of Residents in Long-term Care Policy"

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## SPEAKERS

Jennifer Johannesen, Emily Nicholas Angl, Devora, Gale, Dee Tripp

### **Jennifer** 00:02

You're listening to Matters of Engagement, a podcast examining issues at the intersection of health, healthcare and society. I'm Jennifer Johannesen.

### **Emily** 00:12

And I'm Emily Nicholas Angl.

### **Jennifer** 00:17

Hey! So we're back after a bit of a break. This will be our second to last episode in this Health Policy series and we're busy sorting out what's next. So stay tuned for updates.

### **Emily** 00:29

Okay, so in this episode, we're finally getting to a topic we've been thinking about for a long time. It's super current, but also kind of evergreen. Meaning, it's kind of always been an issue and probably always will be.

### **Jennifer** 00:46

Yeah, we're talking about living in Long-term Care, and what it's like from the residents' perspectives to live under conditions that were not necessarily determined by them.

### **Emily** 00:55

And we're also exploring what's required in order to give residents the autonomy they seek.

### **Jennifer** 01:00

So in this episode, we're going to hear from two people who live in Long-term Care and who also lead their respective Residents' Councils. You'll hear them share some of their experiences about living in Long-term Care. But more importantly, we want to amplify their observations and insights about how residents are included in decision making...

### **Emily** 01:19

...or not...

### **Jennifer** 01:20

...yeah, or not, through their involvement in Residents' Councils.

**Emily 01:23**

For added context, we also speak with Dee Trip. She's the Executive Director of the Ontario Association of Residents' Councils. We'll hear more about their work shortly.

**Jennifer 01:36**

We thought this would be an interesting addition to this Public Engagement in Health Policy series. Because it's a model of engagement and advocacy we haven't really discussed in any episode yet. It's a kind of hybrid approach. There are formal structures in which residents are invited to participate....

**Emily 01:51**

...you mean the Resident Councils...

**Jennifer 01:53**

Yes, each home has one actually has legislated to have one. So that's the engagement part. And then there's the advocacy part, which is where the Ontario Association of Residents' Councils - or OARC - comes in. We'll unpack all of this throughout the episode.

**Emily 02:11**

Okay, so let's talk about residents for a minute. The people who live in Long-term Care homes. Now, I think there's a wide assumption that everyone living there could be classified as frail and elderly. But the truth is, there's a wide range of people with varying needs. And certainly there are older folks, people with disabilities or some kind of cognitive change... but not exclusively. What they have in common is a need for enhanced supports for activities of daily living. But the residents' ages and needs are actually quite diverse.

**Jennifer 02:45**

Yes, but despite this, Long-term Care or LTC residents are often painted with the same wide brush. They're thought of as vulnerable and in need of special protection. Yet the homes are almost perpetually underfunded, and understaffed.

**Emily 03:02**

This can create conditions of too many restrictions and not enough services.

**Jennifer 03:08**

And too often, what gets overlooked is a sense that residents may actually have interests and priorities of their own. And while structures like the Residents' Councils make an effort to include resident voices, there's just not always enough of a foothold to call it self-determination or even self-advocacy.

**Emily 03:28**

Yeah. And it's partly because Long-term Care is subsidized by the government. Residents are subject to the rules and conditions imposed upon them. It's classic institutional living. And it may not feel that you have much control over your own environment. And, you know, let's be honest: residents' ages, capacities and life circumstances may not be conducive to spending much time on advocacy.

**Jennifer** 03:54

Which is why in this case, having the support of a dedicated umbrella organization like the OARC is so helpful. They understand the ins and outs of the legislation, the politics and the power dynamics.

**Emily** 04:08

Yeah, it's an interesting angle to explore because it's an example of an engagement practice that's bigger than just a few individuals recruited into an Advisory. There's a broader agenda here - and one that aims to serve a common good for the residents. And there's recognition of the obvious need for professionalism and political savvy.

**Jennifer** 04:29

Okay, well, let's jump right in. Let's start by meeting our guests. There's Devorah...

**Devora** 04:34

Hi, hello, everybody. I am a resident in a Long-term Care home for...it will be 11 years in February.

**Jennifer** 04:43

And Gale

**Gale** 04:44

So I'm Gale, I am in Ottawa, been here for two years. So I arrived in the middle of COVID, which is, you know, it's....[fades]

**Emily** 04:53

Great to hear their voices again. We had the privilege of talking to Gale and Devorah, who each live in a different Long-term Care home. And we wanted to get their perspective on living in an LTC, to better understand the extent to which they're able to contribute to policy and decision making

**Jennifer** 05:09

or not

**Emily** 05:10

Yes. Or not.

**Jennifer** 05:12

Okay, so let's hear a bit more from our guests. We asked how they came to live in Long-term Care. Here's Devorah.

**Devora 05:19**

The reason I'm in Long-term Care is because I had a disability I couldn't walk. I wasn't in long current Long-term Care to just be put there to, to wait to die. I went into Long-term Care because I couldn't manage by myself.

**Jennifer 05:41**

Like Devorah, Gale also lives in Long-term Care, so she can receive the type of support she needs to live as independently as possible.

**Gale 05:49**

I am here only because of a physical challenge and requirement for supportive help. My intellect is completely intact. And so I find it quite challenging being in Long-term Care, in that, given that capacity,

**Emily 06:05**

Gale explained how not everyone living in Long-term Care has a cognitive change or impairment.

**Jennifer 06:10**

Yeah, now she herself is a bit of an anomaly in the Long-term Care context, as she's relatively young and able to communicate and advocate for herself. We asked her to elaborate on how she feels about being in the minority...

**Gale 06:24**

...statistics are currently about 80% of the people living in Long-term Care have some form of dementia or Alzheimer's - so some decreased cognitive ability. And you know, everybody has a path, of course, into Long-term Care. But part of the problem or part of the challenge for people like Devorah and I living in Long-term Care is that fact, is that percentage of people where, when you live in a democracy that you know, gears their programming or care to the majority, to suit the majority, then when you're in that 20%, or 15%, minority, it becomes really challenging to live in that space.

**Emily 07:11**

Okay, so this is really interesting and something we'll pick up again later. But with such a wide spectrum of needs and abilities in Long-term Care settings, trying to focus policy on resident priorities and interests is a complex undertaking.

**Jennifer 07:27**

Yeah. And also for Gale this presents issues at the interpersonal level. People make a lot of assumptions about her capacities, because of where she lives.

**Gale 07:36**

It's one of the big challenges, I think, for Long-term Care and for the health industry in general in that there is nothing between living by yourself, being able to care for yourself, or requiring help. And the only solution is Long-term Care because Independent Living isn't available. So when you require physical help, there is no other

alternative. And nothing bothers me more than someone assuming that I have a diminished capacity and then approaching me at that level. So yeah, I think that's probably why I feel the need to set the stage properly.

**Emily** 08:22

Gale and Devorah have very different needs. But they share a common desire to live as independently as possible. And as we're going to learn, there are many, many barriers to this happening. And at the root of a lot of those barriers is stigma and discrimination.

**Devora** 08:40

There are perceptions. And it upsets me when I hear nasty comments about people who have to maybe go into Long-term Care, where one lady said she would rather be naked in a flower field that can go into Long-term Care. That's not very complimentary. And people call us nursing homes. Well we're not nursing homes. We live active, fully. What's the word I need? ("Engaged?") Thank you - fully engaged in all walks of life as best... I have to clarify this... as best as we can. Not all of us are similar to Gale and myself when it comes to cognitive ability.

**Emily** 09:44

By the way, that additional voice was Melissa McVie from OARC. She was helping Devorah get connected for our call.

**Jennifer** 09:51

Okay, so like usual, we've stumbled into a couple of our common recurring themes. Definitely one is representation or representativeness. And we also have issues of fairness, autonomy rights. Both Gale and Devorah characterized living in Long-term Care homes as living like second class citizens.

**Emily** 10:12

So to be clear, we didn't really talk about quality or consistency of care - though that might be a topic for another episode. But rather, they feel they're subject to different rules than everyone else, only because of their address as LTC residents.

**Jennifer** 10:29

Okay, so this is a good segue actually. Let's pivot to talking about Residents' Councils, and the role they play in helping residents advocate for what they want and need.

**Emily** 10:40

Okay, let's bring in Dee.

**Dee** 10:43

Well, hi, my name is Dee Tripp. I'm the Executive Director of OARC, the Ontario Association of Residents' Councils.

**Jennifer 10:52**

OARC is a not for profit association funded primarily through the Ontario Ministry of Long-term Care. And their role is to support Residents' Councils in Long-term Care homes.

**Dee 11:03**

So in Ontario, mandated by law, every Long-term Care home must have a Residents' Council. So OARC provides support, education, advocacy, to all Long-term Care homes' Residents' Councils, so that their Council can be as effective as possible. The function of our Residents' Council, when you strip it all down, primarily is twofold. One is that a Residents' Council in a Long-term Care home provides an avenue, a safe space, for residents to provide peer to peer support. To talk about whatever's on their mind, to share with each other, the good, the bad, the ugly, the celebratory pieces, to build friendship and relationship one with another. The other piece of a Residents' Council is to develop and present consensus decisions and opinions to management teams in each respective Long-term Care home. So that quality improvement and changes can be made within the operations of the home that reflect residents' desires and lived experience. We always say that, by virtue of who they are, living in Long-term Care homes 24 hours a day, seven days a week, are experts in their lived experience. So we firmly firmly believe that no policy, no decision, no direction, should be made or developed without tapping into the resident opinion.

**Emily 12:44**

Okay, so a couple of things to mention. We won't get into it here. But we just wanted to call out that we've done episodes on the notion of expertise, and interrogated the idea that lived experience is an expertise in its own right. So if thinking about this further interests you, we've put links to relevant episodes in our show notes.

**Jennifer 13:04**

Yeah, that will be a fun rabbit hole for someone to go down! Okay, so the other thing we noticed is that Dee refers to "consensus decisions and opinions", which suggests that there's general agreement among residents. Now that can't be easy to attain when there's such a diversity of needs, abilities and capacities. A point that Devorah illustrates well.

**Devora 13:27**

You can't paint all residents with the same brush, right? And so we have to be mindful of that. I think maybe there are three of us or four of us. Or maybe five at the most I can sit around and chat.

**Jennifer 13:49**

Yeah, so this was shared by Gale as well. In any Long-term Care home, there are relatively few residents who have capacity to hold detailed conversations or clearly express their needs. So we wanted to dig a bit deeper into understanding how Residents' Councils work, and to what extent they do actually represent the full diversity of the resident population.

**Emily 14:11**

To get us started, we asked Gale to describe how she got involved in her home's Residents' Council and also how she got involved with the OARC.

**Gale 14:20**

In the first six months of being here, I was already noticing issues problems, challenges that myself and other residents were having and thinking: there's got to be a way to address these things. And it was the Recreation Manager that approached me and said, "We are resuming our Residents' Council after being on hiatus through COVID and we don't have a leader right now in the Residents' Council. And you seem to would be focusing on a lot of the issues that would be handled by the Residents' Council anyway. So how would you feel about, you know, putting your name forward to act as president?" So that's how I ended up at Residents' Council. Through that I came to OARC because our Residents' Council has... you know, OARC has a lot of documentation prepared for how to run an effective Residents' Council and samples of, you know, agenda forms and various documentation, that kind of thing. And that's how I first learned about the OARC and just in questioning some of the aspects of running a Residents' Council, became more involved with OARC. Which became a secondary intellectual outlet for me. As far as our Residents' Council here goes, there are very few people who are either interested or capable of participating in Residents' Council. So we don't have a formalized executive for the Residents' Council. I act as President and we have someone who takes notes. And that's kind of the the extent of our formalized structure. Other than that, everyone who attends participates. Everyone has a voice. And there is a portion of the agenda that allows for open communication between all of the residents. And it that seems to work really well for us.

**Emily 16:49**

Devorah also shared her experience with her Residents' Council.

**Devora 16:53**

Okay, so what Gale said is applicable to my Residents' Council. But you have to realize how, sometimes, you need to handle this by getting to know your residence. I have residents outside my door, and I know them. They don't speak one of them makes a sound and she grabs me when... they all grab me when I come out the door. And they want to speak to me, they make noises, they touch. There are different ways of speaking with these people. They are residents. Every resident that lives in the home has a vote, or a voice, in Residents' Council - every single person, regardless of their cognitive ability. The people with more cognitive ability are probably better aimed at running the Residents' Council, which is a terrific organization. It's, as one of our residents said, it's a lifeline between a home and the residents who live there. And so this is how residents who can't speak, who I tried to get to know them and know their likes and their dislikes. Because I'll tell them they look nice. And they'll pat me - if I pat them, they'll smile. Um, I can read them. I really can. I can read them. One lady here loves bananas. So when I have a banana I always give it to her, you know? Another lady likes yogurt. Another one like something else. It's amazing how you can speak to them. It really is.

**Emily 19:06**

Okay, there's a lot to think about here.

**Jennifer 19:09**

Yeah, a lot. Okay, so first of all, Devorah is absolutely right in saying that nonverbal communication is an important part of developing relationships and getting to know one another. And I think her point too, is that

people in Long-term Care are far too easily dismissed as having nothing to say. Which of course does them a terrible disservice. But I'm curious how these encounters actually translate into the context of the Residents' Council.

**Emily 19:38**

Like, can you reasonably represent someone's interests just by knowing their personal habits and preferences?

**Jennifer 19:45**

Well, maybe it's a start? Gale elaborated on why these kinds of ongoing personal interactions really matter.

**Gale 19:53**

The work of Residents' Council doesn't just happen during the meeting. It happens talking to people outside of the meeting. People either come to you with issues or you just hear about things as people are chatting and I take note of that stuff. And so when I get to Residents' Council, the formalized meeting portion, there may or may not be people in the audience who are... I don't mean audience, but in the team that are bringing forward an issue. But if there isn't, I have all of these other things that have come up, cropped up since the last meeting that I've heard about or people have come to talk to me about. And I'll simply bring it up, as you know, someone has expressed the following. And bring up that concern. And sometimes it spurs other conversation with other residents, and sometimes it doesn't. But it's always actionable by the Residents' Council. So the formalized portion happens once a month, you know, in your home, but the process of Residents' Council is an ongoing thing.

**Emily 21:06**

So we brought the same question to Dee at OARC. How do you try to ensure that the Residents' Councils indeed reflect the consensus decisions and opinions of the residents at large, when many of the residents can't contribute directly?

**Dee 21:21**

That is the million dollar question that we grapple with. The reality is that within Long-term Care homes, anywhere from 65 to 80% of the residents who live in the homes have some sort of cognitive change, which inevitably means that many, many people are unable to speak for themselves. Devorah has been with OARC for over 10 years. And she has said many times that being involved with OARC has saved her life, because she had, you know, many of the activities that are provided for and planned for in Long-term Care homes, target or serve residents who are unable to speak for themselves or who are living with some sort of cognitive change. So it's very, very important that we provide an opportunity to link many of the residents in Ontario who are not living with cognitive change so that they can share their experiences.

**Jennifer 22:32**

So what I'm taking away is that this issue of varying levels of cognitive capacity is not an easy problem to solve. And what Dee mentions here maybe speaks more to their social mandate of connecting residents to share their experiences and provide support to each other.

**Emily 22:52**

Mm-hm. But related to advocacy? Dee went on to explain that family members play a vital role in helping to round out the contributing voices.

**Dee 23:00**

Part of the magic that makes that happen is when Resident Leaders in a home work with family members, essential family caregivers. Now the Residents' Council meeting proper is a meeting that is... only residents attend those meetings and Family Councils - only family members attend those meetings unless other people are invited. So we do not advocate that residents attend Family Council meetings or vice versa because the conversation changes. But what we do promote and encourage is that residents have opportunities and seek out opportunities to talk with essential family caregivers to learn about their friends, their colleagues, their co-residents, to the best possible degree that they can.

**Jennifer 23:55**

Okay, so we know a bit about the Residents' Councils themselves. Now they get support from the OARC, which residents can also be involved in. For example, the OARC Board of Directors has four spaces for elected Long-term Care residents.

**Emily 24:03**

Yep. And they also have an advisory group called REAL, which stands for Resident Expert Advisor and Leader.

**Jennifer 24:18**

Right. Here's Dee.

**Dee 24:20**

This group is made up of residents who live across the province. We have capacity for 12 resident REAL group members and this is our group that is really boots on the ground. These Resident Leaders participate in media consultations, government tables, they speak with researchers. They speak at colleges and universities and high schools. They contribute to OARC's capacity in truly representing, again, the consensus view of residents across the province, because these resident leaders are from across the province. And that's how I know Gale and Devorah. Gale and Devorah are Resident Leaders with OARC.

**Dee 24:21**

So both Gale and Devorah have an on the ground perspective as well as a bird's eye perspective through OARC. And in our interviews with them, it was impossible not to talk about the pandemic and its impact on a number of fronts.

**Emily 25:30**

Yep, COVID threw everything into turmoil. Devorah shared with us some of what she experienced as a resident.

**Devora 25:38**

As I told you, I was in Long-term Care eleven years, so I went through the full pandemic. For me, it was a nightmare. They took me out of my room, gave me a bin and told me to pack five changes of clothes. And wherever else I needed. And this was nine o'clock, and I was moving at one o'clock. I couldn't take my computer. I managed to take my iPad and my phone. I insisted - I'm not going out of here without those things. And they put me in a room. Everything was covered with black garbage bags. Had no room to hang my clothes. I had no room to put any toiletries. And the only person - people - I saw were people with masks. All I saw were eyes. If not for OARC I would have never known what was going on. Our communication in the home was nil. And I was in that room for three and a half months.

**Jennifer 27:04**

What an experience, and probably not unique.

**Emily 27:09**

And maybe needless to say, there was no active Residents' Council.

**Devora 27:14**

I was gonna say that, yeah, we had no Residents' Council. We just resumed a couple of months ago. After three and a half years.

**Jennifer 27:28**

You'd think that having an active Residents' Council throughout the pandemic would have been a priority, even in times of isolation and uncertainty. I mean, it's not like there wasn't the technology or means for residents to connect. Gale commented on this as well.

**Gale 27:43**

I think that during COVID, it probably was the most important time to have an active Residents' Council, if for nothing else but to filter communications through. Because the biggest problem during COVID on the resident base was lack of knowing what was going on. Lack of knowing what the restrictions were, the changes to the restrictions, new restrictions, new guidelines, new rules. It was abysmal. And an active Residents' Council could have mitigated that a little bit. So yes, it's unfortunate. I was fortunate in that they resurrected our Residents' Council as early on as they did, because there were places that was much much later before they got their Residents' Council up and working again. And your Residents' Council is your line into the administration. It's your, you know, it's your vehicle to the organization and changing policy within the home or trying to enact change. So having nothing in place for a length of time can only be detrimental to the resident base. And that's really unfortunate. A home can put a Residents' Council into place and check that box. But it doesn't mean that you're going to have something that perhaps works or works well or addresses you know, resident problems or challenges. For nothing else but to protect resident rights... you know, a Residents' Council is imperative. Everything else is kind of icing on the cake. But first and foremost, you have to do that.

**Emily 29:53**

Okay, so, what Gale is describing here is something really fundamental. Of course, communication is important. As is a sense of community that Dee described earlier. But Gale is talking about residents' rights. And for Gale, it's about having the same rights as everyone else. Including peers who don't live in Long-term Care.

**Jennifer 30:14**

Yes, in the context of COVID, she's referring to the fact that residents of Long-term Care homes were subject to rules and restrictions that people living in their own homes didn't experience. And this continues currently - there are more restrictions, if you're inside the four walls than if you're outside the four walls. Both Gale and Devorah see this as unfair.

**Emily 30:36**

Yeah, I mean, I can see their point. I think wider society has thought of people in Long-term Care as needing special protections.

**Jennifer 30:43**

And plus the fact that it's a workplace with casual or agency staff potentially moving from home to home. So precautions are important.

**Emily 30:52**

Yeah, that too. I mean, it's easy to assume that LTC homes should have the most restrictions. And yes, there's a case to be made... But the argument that Gale, Devora, and the OARC are making is that residents should have had a say. They should have been better informed, should have been involved.

**Jennifer 31:11**

Right. And there's so much variance from home to home in terms of how Residents' Councils are run, and the extent to which they have actual influence, which is why mandates requiring Residents' Councils are really only as successful and meaningful as each home makes it. There's so much inconsistency. Devorah notes how important it is for the Residents' Councils, to have the support of management in each home.

**Devora 31:36**

it's essential that the residents have a relationship with the management, especially with the Administrator. I feel it's very important for the Administrator to be visible. I don't like people coming up to me and saying "who's that lady?" Well, that's the Administrator! "Oh!" I feel that residents need to be better informed. To make a better home and Residents' Council, you have to have people work with you. There has to be a relationship between all the management, specifically the Administrator, but they're also management. Like there's a girl, the receptionist, she gets all my faxes. And she brings everything down to me as soon as it comes in. That's also part of working with Council.

**Emily 32:51**

Right. So every interaction, every bit of support, it all matters. And the work has to be taken seriously, treated it as important. So here's Gale:

**Gale 33:04**

I think that an effective Council is going to be able to collect input from the residents and have a process to action those things, or to bring them to the attention of the departments that require the information. So that's one piece. So you have to have the Residents' Council working as an effective vehicle. Then the problem is that you have to have the recipients on the other end of that request for information to be of a culture that is working towards the best for the residents. And that's not always the case. It's often if you bring up an issue or a problem or challenge, something that's not working - you can check the box to say you've actioned something and still be ineffective. By that I mean, if I bring a problem to a department's attention, if all I get as a response is the rationale for why it's the way it is? That's not helpful.

**Jennifer 34:27**

Okay, so what we're hearing is that it's all well and good to mandate Councils, but they have to be properly resourced and supported. And that's no easy task. Here's Dee.

**Dee 34:40**

The compounding issue is across the board. Every department in Long-term Care there is a human resource crisis. The sector is drastically understaffed and it was understaffed prior to COVID. During the last three years there has been a hemorrhaging of team members within the Long-term Care home sector, and we are drastically understaffed now. In the best of times, when Residents' Councils are functioning, they are under resourced, and with a lack of staff in homes now, the Council's are often pushed to the backburner, supported off the edge of someone's desk. And quite frankly neglected.

**Dee 35:25**

For something to be mandated in implies that it's essential. For something to be essential, it implies that they need to be resourced. OARC's recent proposal - we do have a proposal in to the Ministry of Long-term Care for additional funding - the title of our proposal is "Legislatively mandated, operationally essential" to stress that very point. During the height of COVID, Residents' Councils were neglected and they fell silent in many homes. In addition to that, residents told us that any positive steps that their home had taken with positive cultural change had gone backwards 10 steps during COVID. And what I mean by that is communication with residents, authentic engagement, conversations and just raw communication between residents and management was very, very poor. Residents were isolated, they were lonely. And so further to "Owhat's the problem?", we have to understand the context from which we're coming right now, with the past three years of drastic and ongoing restrictions. Residents' Councils are the one and only protected venue in a Long-term Care home for residents to shape the place they call home.

**Jennifer 36:59**

So OARC is seeking more funding to help support their work both in the homes and provincially, which will definitely help with what they're trying to achieve. But here's the thing...

**Dee 37:10**

You know, it's not about money.

**Jennifer 37:13**

It's not about the money. Or it's not only about money.

**Dee 37:17**

It is fundamentally about authentically believing in the mandate. As human beings, we do what's important to us at any given moment in any day, every day, we do what's important to us. And if supporting and recognizing seniors, and thereby residents, in Long-term Care homes... if valuing people who live in Long-term Care homes is legitimate, then you pull it the stops. You know, no matter if you're a policy maker, no matter if you're a front line team member in the home, if you're there because it matters, and you are living, breathing, working, and developing policy and rules and regulations to support the fact that people matter... then the rest is just gravy.

**Emily 38:25**

So yeah, this came up a lot with all three of our guests. It's not only a question of having proper supports, it's also about needing a wholesale cultural change in terms of how people, the public, think about Long-term Care. As Devorah mentioned at the beginning, people live in Long-term Care so that they can get the support they need, and it shouldn't be thought of as a place that people go to die.

**Jennifer 38:50**

Yep, it's likely this mindset that has held back progress in terms of giving Long-term Care residents an actual meaningful say in how things are run.

**Dee 38:59**

So often, government policies or even home management policies say we are the professionals, we will "do to". We will design policies that protect residents from... but residents have said to us, "You know what? We want to be part of the solution. So give us the tools that we need so that we can live with and connect well with people who can't speak for themselves."

**Emily 39:25**

For Gale, being part of the solution means setting the stage for collaboration.

**Gale 39:30**

So, first, you need an effective Residents' Council, then you need a collaborative culture. And that's a piece that's really missing. Collaborating with residents is not standard practice in Long-term Care. And it truly is a culture shift. And that's where we need to get to. Historically, Long-term Care homes or nursing homes as they were called before that, homes for the aged, they were run by the administrator. The administrator or the CEO made the rules, and everyone under them followed them. And they were all acting for the quote unquote betterment or the best environment for the residents. But only as they saw it. Only as they perceived the best thing for the residents to be. The culture change is that the residents are saying, "We can speak for ourselves. We can tell

you, what's the best for us." And that's when Residents' Council steps in and says, let me act as a, an organized an organized group to highlight these problems, so that we're going to distill the information from all of these inputs into a thread of process that the Residents' Council can act upon, and then liaise with the management team. That's the ideal. As long as you have a collaborative environment and an organization that is willing to give up that control.

**Jennifer 41:31**

Dee takes this idea a step further. Collaboration is important, of course, but the integration of residents' needs and priorities should begin much sooner.

**Dee 41:41**

So often, when there are decisions to be made in a home, or decisions to be made at a policy level - whether it's government level, or at the home level, the policy is drafted. And then if residents are lucky, they are invited to review something that's already been crafted. So what I'm saying is that at the design stage, to pull in an ideas sharing opportunity with residents to identify truly what is the source of the outcome that you're looking for? What is the the problem, the issue, the challenge that you're trying to solve, as identified by residents? Many of the decision makers in government likely have never set foot in a Long-term Care home, perhaps have never spoken with a resident. And that matters.

**Devora 42:51**

Yeah, it's so important. That decision has been made before. I mean, why is the sense to making a decision for people who live in a home, what you think is right for them may not be what they think is right for them. So what is the point? If I'm supposed to think of where I live as my home? There are a lot there are a lot of things that are ongoing, right? I can call it my own. It has to change.

**Jennifer 43:36**

Hi Emily!

**Emily 43:38**

Hey, Jen. So key takeaways?

**Jennifer 43:42**

Well, first and foremost, I think there's no reasonable argument against residents being more involved in determining how they should live their lives, not only in terms of how their homes are run, but also in terms of weighing in on their own acceptable degrees of risk.

**Emily 44:00**

Yeah, I totally agree. This shouldn't exactly be controversial. But, you know... come to think of it... with all the COVID media coverage over the past couple years... we've kind of heard from everyone but residents. Their voices were drowned out by health professionals, politicians, and even family members and caregivers.

**Jennifer 44:20**

Which brings us to another takeaway, I think, and that's the critically important nature of the involvement of the OARC.

**Emily 44:28**

Yeah, typically in organizational health care, we see patients, caregivers and family members, individually invited to participate in various councils or advisories. We've talked about how this may fulfill institutional agendas, but may or may not actually improve conditions for patients more broadly.

**Jennifer 44:48**

Yeah, exactly. But with this larger umbrella organization, there's a better chance for impactful representation at the different levels of government and for the homes themselves to respond more positively to the Council. It's organized, politically attuned, and focused on the needs of residents.

**Emily 45:05**

Yeah, this is kind of a departure from typical organizational engagement activities. I guess more like a hybrid model. There's individual participation at the level of the home, but with support and guidance of a larger, dedicated organization.

**Jennifer 45:21**

Yeah, it's really interesting. But I mean, not without some complexity, the Ontario government actually funds the OARC. So their advocacy has a particular tone, let's just say. Dee mentioned at one point that their approach is not about protesting and noisemaking. It's about ensuring they're at the right tables with the right people, and continuously seeking venues where they can amplify resident voices. It's a more collaborative type of advocacy.

**Emily 45:49**

Sure, yeah. That makes sense. Which I'm sure comes with some trade offs. But what's super clear is that OARC is performing an important function for Residents' Councils, and therefore for residents themselves. We asked Dee for some final thoughts on what needs to change.

**Dee 46:13**

What needs to change is a culture shift. There's a predominant view that people who live in Long-term Care are, you know, plucked out of community and put somewhere else. And what we're saying is that, you know what? Residents who live in Long-term Care are just as much a part of the community as they were prior to moving into Long-term Care, that they are vital contributors to decisions and even residents who cannot speak for themselves are able to contribute to their own quality of living. So I guess what needs to change, bottom line, is an understanding that even in advanced age, with comorbid illnesses, with cognitive changes, people still are valuable contributors to community, to their life. It's an underpinning of everything that we do that residents are full contributors, full human beings. And I think Gale and Devorah are excellent examples of that.

**Jennifer** 47:30

Big thanks to Devorah, Gale and Dee for sharing their experiences and insights. And a special shout out to our friend Christa Haanstra, for connecting us to OARC and helping us navigate this topic.

**Jennifer** 47:44

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