

Genia: Welcome to the good things in life podcast. I'm Genia Stephen. Today's podcast episode is a recording of a live presentation given by Janet Klees. Janet has been involved in the lives of people with disabilities, their families and allies and community for over 30 years. For 21 years until 2014, she was coordinator with the family govern Deohaeko Support Network almost from its beginnings when families designed and built a 105 unit housing cooperative within which seven of their sons and daughters with disabilities now call home and from which they live typical and full lives and community. Currently, she's the executive director for the Durham Association for Family Resources and Support, which is a values based organization in Ontario, Canada that supports the capacity of families to design and implement good lives in neighborhood and community for and with their sons and daughters with disabilities. Janet has been deeply affected by the lives of people with disabilities and their families that she has come to know within that group and through other life experiences.

Genia: She is the author of three books which are directly rooted in the Deohaeko experience. We Come Bearing Gifts. Our Presence Has Roots and Deohaeko Decades, which are now sold around the world. Janet has also written countless other published articles and documents to support her work in thinking. Janet's work centers on individually designed arrangements and she's especially concerned that families in their allies and support workers are well supported to think through practical principled ways to ensure their family members live meaningful, involved, and secure lives within their communities. At this point in time, Janet is known for her work on identifying and teaching a practical strategy, building a context for relationship, which is the topic for today's podcast episode that is able to bring relationship roles and places of belonging into the lives of people. She's also known for her work on the support role as a unique and often poorly understood or executed role and her development of the family group model underpinned by a collaborative coordinator, her support of family leadership initiatives and her focus on shared decision making all within a coherent framework of principled decision making rooted in social role valorization. I'm just going to let Janet take it away.

Janet: I'm signing up on the chat and I actually knew some names so, I feel like I'm in a room or world full of people with some familiar faces and some new ones. That's wonderful. People who know me a little bit know that I can talk an awful lot, but really, I only have like 45 minutes or so, and then lots room for questions. So, I will kind of touch in on some of the things that I have found important over time with the focus on a relationship because that is something that just draws many, many people to kind of think about what next. So, I was really thinking for today's time, I'm going to try to share three sets of ideas at. First of all, I really, I'm going to go over this little strategy that I'd worked away at over the years called Building a Context for Relationship simply because I have taught it to family members, to paid supporters, to circle members, to people with disabilities themselves and others over quite a long time.

Janet: And I know that regular, ordinary people can take the set of ideas and really make a difference, be really effective in changing the kind of relationship landscape in people's lives by paying attention to four or five different things. So, it's achievable, it's effective. And many of you will know if people who know me will know this strategy. And so, it'll just be a little

refresher. For other people, it'll just be a bit of an overview and if you are intrigued with these ideas, be in touch with Genia or myself and we can direct you to further readings on it. I typically do a full day workshops so, this'll be very, very condensed. And then, because in teaching that situation reminding, I'm going to focus on two longer stories. The second thing I'd like to do is a set of ideas that I just call From My Doorstep, which is just the idea that there are all kinds of things that people who are busy and stressed and have a lot on their plates can begin to do right away, that are small, achievable and hugely impactful, all kinds of things.

Janet: I'm going to spend a little bit of time there. And then I'm going to end with a section that includes, you know, both things that often go wrong. So, maybe I can head people off, give you some heads up around don't go in this direction. And some lessons learned and we'll kind of wrap up with that with, as I said, enough time for questions. So, I'll be kind of watching the time to figure out where that is. Oh, there. So, I can kind of be in line with that. I am going to a zip to slides every now and then and this is a whole new technology for me, so hopefully, I can do well with that. So, building a context for relationship, this little strategy, I work this out, as I said, with people with disabilities and families and really dedicated page support people over time and really people searching how to bring a greater degree of relationship into people's lives.

Janet: And I think before we even got to the how to, what was very important to us was to figure out why did this matter in the first place? Why is this really important? Because unless you're deeply compelled to do this, other things might be easier or good enough. So, in our thinking and talking, it became clear that relationship brings at least two things of great value to our lives. And the first is it brings a degree of richness and stretching in our lives. People in relationship with us, get us to do things we wouldn't ordinarily try. Bring their own ideas into their lives, that richness that we as human beings just love. So, why wouldn't we want to make sure it's there for the people we love? And then secondly, for all of us, relationship brings a degree of safeguarding that people stand up for us to have our back.

Janet: And when we have a family member or a dear friend with a disability, we know that despite our love and clarity on the worth of that person, society in general doesn't highly value our loved ones. And so, they will always be somewhat vulnerable to people not looking out for them, not allowing the best things to happen for them. And so, in relationship when people have the back of a person with a disability that takes on very, very life defining kind of qualities. And I don't know, a single parent who feels like they can end their life comfortably without knowing that there are at least a few people and freely given relationship with their son or daughter to do that very thing. So, richness of life and that safeguarding element, that's why we want to bring relationship into people's lives. And then, I'm onto, you know, what's missing in people's lives?

Janet: We see people around, the next thing we had to clarify is what's missing and what is it that we're trying to achieve? And what was clear to me and the people I was working with? Is that what's often missing in people's lives, our relationships with other people of similar age or a range of ages where other people don't have a disability? And so, one of the things I like to clarify in this strategy is thinking about how to bring about people who don't have a disability

into the life of your son or daughter with a disability. And it's not because I don't value or there is no value in relationship between people with disabilities, but simply by looking around and by what families tell me the gap in people's lives is attracting people to their lives who don't have a disability and who can more clearly bring about those two things that really matter, the richness of relationship even wider and that safeguarding elements.

Janet: So, just to be clear, the strategy I'm going to talk about today is how to kind of nurture, encourage and bring about a relationships into your son and daughter, your family member's lives by people who don't themselves at this time have a disability. And then, so, one of the things we realize right at front, just because we wanted something, we couldn't just make it happen and we had to be more purposeful and more intentional and thoughtful and bringing about relationship. And what we learned over time is that we can't just make it happen, but what we can happen is design a situation which I call a context, a situation in which relationship is more likely to arise. And while it's kind of percolating along relationships developing some other really wonderful things happen with this strategy. People develop identity purpose in their life and feelings of belonging. So, you know, in so many ways we've just found it's a real win-win situation. So, let me just talk to this strategy.

Janet: Okay. Can you see that, Genia? Good. Great. So, for people who don't have the visual, I'll just go through clearly the five pieces of the strategy called Building a Context for Relationship. And what we're trying to do is to build a situation, prepare situation, organize a situation in which relationship is more likely to arise. And I think you'll see as I go through this, there's many things that we already know. We don't always bring all of these elements together. We forget one, and then the situation is so much less powerful. So, the first thing that we need to think of is we always need to follow the interest with the person. We have to understand who a person is and follow the things that they're interested in. And in some ways, you think, "Well, that's just a very clear. Of course, it would be that."

Janet: But I'm so often, we skip this altogether and have people doing haphazardly, whatever happens to be in our community. And so, I really urge people to take the time. It doesn't matter if this point you have a very young child or you have an adult family member and you'd just like to take a fresh start at things and really start to notice. I'll talk a little bit about this in a bit, but you want to notice what lights this person up? What helps them to really shine? How do you know what they're interested in? What do they follow? And that could be anything from, you know, the people around them to the kind of environments they're in, to kind of following a sports or music or art or a color light, that kind of thing. And just kind of pay attention to that cause that's really important.

Janet: So, that's your starting point all of the time is the interests of the person. And then, what you all need to do is to build a situation where four other things happen at the same time. And I kind of talk about this as like juggling. But we have to make sure that we have all the balls in the air, so we have to make sure that you're going to help this person follow their interest in a place in community that other people typically go in order to follow that interest. You ask questions so, if someone's interested in music, for example, you ask the question, where are the other people in Durham region for us who follow music? And of course, you have

hundreds of answers to that question. And those hundreds of places where people are, who love music should be the places that you focus on for the situation you're creating.

Janet: The next thing you want to figure out is how can a person be present in those places where music is playing, for example, on a frequent and regular basis. And there's lots of reasons for that. But let me just for the moment say that unless people are in places at the same time, the same place, week after week, after week after week, they can't be comfortable and show their best selves and other people can't get to know them. And in this era where we have lots of one-to-one supporters running around community doing spontaneous stuff all of the time. It might look really great and exciting, but if you think about it, you can't build relationship on that kind of haphazard presence. You want frequent and regular presence. And then the third element you're going to look at after following the interest of the person, you're going to find typical places in community where people share that interest.

Janet: You're going to get there on a frequent and regular basis and that you're going to help the person decide who they're going to be while they're there. And we don't want to just get stuck on people being spectators and the preservers. We want them to be volunteers, we want them to be desk clerks, we want them to be fundraisers. And, we'll give you more examples of all of that. But once somebody is some, when someone is somebody in a place, they have a role to play and therefore they are able to make a contribution and it's when you make a contribution well then there's a exchange between people that relationship is even more likely to happen. And then the fourth thing that you have to pay attention to is whether there are other people in the vicinity and you would be surprised perhaps how often we send people off to great places in community on a frequent and regular basis where they get to play a role, have a role in what's happening and they're doing their volunteering in a corner with the supporter, right?

Janet: The only relationship that's going to be worked on is with the supporter and I'll get to issues about that later on. So, that's really how simple the context for relationship is. I only really encourage people to when you are planning out your situation is to kind of tick all of those off. Is this genuinely the interest of the person? Is this a place in community where people have this genuine interest? Can she get there on a frequent, regular basis? Who is she going to be when she's there? What's her contribution going to be? And are there other people present? You know, so, that's the how simple is the strategy itself. I'm going to just kind of say what this is again through two stories, which I'll tell much more quickly than I usually do. Let's see. Oh, these are backwards.

Janet: Excuse me while I flip through. Oh dear, my slides. Anyways, I can do this. Tiffany, where are you? So, Tiffany is a woman who lives in Pickering. And along the way, someone discovered that she had a real interest in color and in, she noticed things very, very carefully and the woman who kind of paid attention to this was herself an artist and she wondered whether Tiffany might have an interest in art. And this wasn't anything that really had showed up any other time of her life, but it's always good to explore. Tiffany was able to explore this and this other artist said, "Yes. Tiffany has a way of coming at her art and I'm paying attention to her heart." Now. It was really interesting because Tiffany is a woman who she doesn't speak and she doesn't even like to hold things on all of the time.

Janet: So, she had to, the artists had to work with her and really find out how was she going to choose paint color, how is she going to decide when a painting was finished, how is she going to decide which painting implements the use? And they spent almost two years in discovering how Tiffany was really going to show that. And once they started, once we understood that Tiffany likes to paint, came out it willingly, came out with a method, we understood that in her heart of hearts, she might well be an artist. And then we could ask that question that I really want people to get fixed in their minds. If this means interest in art and painting, where are the other people in Durham region who are artists and painters, and what are they doing with their time? And this happened about 16, 18 years ago now and we made lists and lists and lists and I can tell you I'm still a part of Tiffany's circle.

Janet: We're still using those original lists today to augment who she is and how she approaches art soldiers. One of her paintings... I want to get to that in a minute. This is another one of her paintings. And so, once we asked the question, "Where are the other artists?", we found that they were members of their art guild, that they had art in different installations around town. We found that they got together and painted in classes like the one you're seeing here. They donated their art, they painted in festivals, they had people over for paint parties, they hung their work here and there and everywhere. And what we just started to do slowly over time. Oh, Jamie is just showing me, she's got one of Tiffany's, that particular picture, the watercolor in her office. So, she is yes, a well-known artist. And over time, so she paints regularly with the group of women.

Janet: The woman beside her in this photograph is a woman who isn't the person who taught her about painting, but she is a group, a member of this group. And that group on noticed that she was really interested in larger, brighter canvases. So, help Tiffany transfer over, you know, to being an acrylic water, acrylic painter. And isn't that what relationship does? It stretches you; it gives you new opportunities as it did for Tiffany. So, one of the things that just like you to focus on in Tiffany's story is we started with an idea that she was interested in color and light and noticed small things and then we gave her a long, regular, intense opportunity to explore that. And once we felt that she was an artist, we helped her slowly take on one after another role in being an artist. And so, what that meant is that what we help Tiffany transition to, from was someone who painted in her spare time or painted as an activity.

Janet: You know, what does Tiffany like to do? She likes to paint. And then our question was, you know, what is she going to do with her time? And you can see that if painting took place on Tuesday afternoon, she had a lot of other time for us to fill in and we were sometimes very, very tired helping her feel her weekend, meaningful kinds of ways. However, once we started to ask questions differently and we thought that Tiffany was an artist, we were starting to ask you know, what do other artists do with their time? Who are they in their community? We asked the same question for Tiffany and then we began to ask, you know, what is she interested in? What might she liked to do? And she explored a whole bunch of things. So, based on just that one role, she has many, many things to do across the week just related to that one role.

Janet: So, this idea about thinking in terms of role rather than activity is so powerful because it gives a much, much richer life. And every time a Tiffany does a different kind of activity. So, on this chart on Monday, she's checking on her sales at an art shop. In the evening, she's going to a local on painting exhibit. Tuesday she's buying her art supplies, she's still doing some painting because she asked her produce. On Wednesday, she's looking, checking out a new shop to sell her art. She might go to her art guild meeting that evening. Thursday she's choosing frames and signing her art. Friday she's going to that art studio to paint with other painters, etc. And it stretches across the week. And so, that's only one role. And every time she takes on another activity, it deepens her identity as an artist in her own eyes and in the eyes of other people.

Janet: So, even though she doesn't speak, if she turns up at her art studio, people say, "So Tiffany, what have you been doing?" The person who's with her can say, "Tiffany went to that new art exhibit this week, done by our friends, so and so, and it was really amazing and you should go along, great." So, they really see her as an artist who's just as steeped in the art world as they are themselves. So, that's what focusing on role does. Remember you've got place; you've got presence and that role. And in her role, she as artists, she's able to contribute in many, many ways. She can, she can sell paintings, she can beautify the world in this way, but she can also volunteer and offer her art at different times. And so, it helps her to become somebody that people know how to relate to. For other artists, the things she is doing and the way she approaches her art is very, very familiar. So, even though she doesn't speak in typical kinds of ways, and even though she needs a lot of support and even kind of getting her lunch ready to eat, they understand some bigger, more important things about her. And you could imagine that that certainly is a foundation for a relationship.

Janet: Oh, I can't believe I... All right. Let me just quickly talk about Rob. Tiffany is one example of using that little strategy and how that deepens, richens life and brings that degree of relationship from other artists and people in the art community into her life. Rob's story developed a little differently cause he's a different person, right? So, Rob is a guy that at one point in life people were sitting down and thinking about who is Rob going to be in his life, especially in his work life? How can they contribute? Who could he be? And one of the things we paid attention to or two things actually, I wanted to tell. The first story was we knew that Rob liked music generally, lots of people do. And again, we went on an exploration to find out what kind of music and we found out that he loved Symphony Orchestra kinds of music.

Janet: And so, he was introduced to be a fan of the local and symphony orchestra. He goes, went to their practices on a very, very regular basis. And the thing I want to talk about in this little story, it's got a bigger piece to it. But the piece that's interesting to many people is lots of people have said to me, well that's a pretty interesting story. And my son also loves music, but there's no way he'd go to a rehearsal and hang around. And we said, "Oh, well. That would've been Rob." Because Rob isn't somebody that we can explain really well something to that's going to happen in the future. He really has to experience it. And so, for Rob, what we, with the permission of the conductor, we arrived, we found out that at the halfway through the evening rehearsal, they had a coffee and donut break, and one of the things we know Rob loves anyways is coffee and donuts.

Janet: So, we made arrangements that he would arrive only five minutes before that break would happen. So, he walks into the room, there's this beautiful music playing, he's in his element and just when he's beginning to wonder, where is this going? What's going to happen? Everything stops. He gets coffee and donuts. And then there's more music again. He stays for about 10 minutes. He's had enough and he's on his way. And we spent months and months and months helping him get used to what this evening was going to be about and stretching his time until he could arrive 10 minutes before the rehearsal started and begin to greet people and get to know them. So, that I just wanted to add that in because people aren't always automatically able to be present in the same way and we just have to be thoughtful about that.

Janet: Like everything else. The other thing that Rob, when we were thinking about how we would contribute and be a part of his working community, really thought of it, his interest in young children. Again, I don't have a lot of time to go into all the details, but let me just say that Rob doesn't like to touch your whole thing's very much and so, he wasn't going to be the practical help in the kindergarten or daycare like people would see as an assistant in an ordinary kind of way. And so, we had to think about what else he would have to offer. And what we discovered after, you know, really weeks and weeks of conversation, was that children on are different around Rob. They really noticed him. And because he's got such a calm, gentle personality they ask lots of interesting questions and they learn a lot.

Janet: And we use this idea to understand that Rob's contribution was that he has an ability to give young children a positive experience with difference and diversity with his mere presence in a room. So, when we kind of called around to daycares and told people that we had a man, you know, who is able to bring this quality to their classroom, he got a two different kind of offers of taking up this role in his community. So, Rob is now, you know, an assistant, we call a mum commuted Africa integration, no inclusion ambassador or something like that, in this daycare. And it really, you know, helps the children kind of to understand that there's many, many different ways be human. And the one of the things that, this is how relationship develops.

Janet: We follow Rob's interest in children and we, I don't have those pictures. And we bring it to a place in community where he is kind of is very welcome and he's got really good connections with the other staff members there because that's who he is more in line with. We're not expecting ongoing relationships with children who will move off, but the teachers who were there and are other adults. And over time, we noticed that the kids were getting so used to him, he was doing his job so well that they weren't paying as much attention anymore. They come over and give them drawings and stuff, but we've wanted something more involved. And so, we thought that he would bring in a series of photographs. We get someone to take pictures of human nature. And again, because relationship was important, we ask somebody who was a homeschooling mom as it turned out to do this, she saw the win-win, brought her kids, went with Rob to a park, took some pictures of the park.

Janet: Rob's in some of them. They were so beautiful, we decided to turn it into a book. So, we went out and recruited a writer and then because we had no money, we recruited a technology guy who could turn this into eBooks and we could sell them online without paying a penny.

And so, in the end, what Rob has is a four-person collaborative that is able to bring a series of books together. He's got six books in the series now all-around nature and whatnot. The next series that they're thinking of doing, the teachers have said to be really, really great if he did a series on the instruments of an orchestra. So, where do you think he's going to go back to base on relationships you've had in the past to do that a series of books? He'll go back to the orchestra of course. So, both of these stories are long stories that take place over time. They've, we've intentionally and carefully built the context around it and we've done it again and again and again.

Janet: Every time a new role is taken on for Tiffany and her art world, we make sure it's a typical place in community where she can be on a frequent and regular basis. She has a role to play and other people are present. And we just tick that off all of the time. And it's this strategy which is really quite simple, that has really made such a difference. We've got something to kind of get back to and to keep us on track. Now it's clear to me that, you know, over time when I talk to people about these strategies and whatnot and sometimes, often actually, that people get a little bit overwhelmed the idea of a 16 year trajectory over being an artist, which, you know, all artists only take it one day at a time.

Janet: But, getting a toll hole, getting a start, I think, I want to talk about a bunch of ideas that I call kind of from my doorstep. How can I do something that begins right now, right away? Because time is so short or I have no funding or very little limited support funding or you know, energy is really poor right now. Or I've got aging parents also to look after or a job or whatever. So, I really understand that kind of a tight, tight fit in life. And so, I think that some of the work that you can do, can really make a big difference and doesn't need to take a lot of times. That things, if you plant the seeds and kind of nurture them to grow up, things can develop with a lot less energy but great intention over time.

Janet: So, here are just a few ideas that I think about. The first is you can't implement these kinds of ideas. You can't build these kinds of ideas without first of all being really clear on the gifts and contributions of your family member. If you understand, if you, you know, are feeling uncertain about your family member, if you feel they are a burden or a hardship to other people, you're not going to be able to talk about them in ways for people to see their humanity, to see their gifts in the contributions that they can be. So, this is real head work and it often takes a lot of talking through with other moms, other people who are very supportive in your life. Because from the youngest age, what the society and especially the medical community has helped you to focus on our, everything that, that your son or daughter can't do.

Janet: And you need to take periods of time every single day. Put that aside and delight in the child that you have. And you know, you need to think about those things, you need to write them down and you need to experiment with them. You need to use them. When you introduce your son or daughter, you need to point these out, these things out to other people. So, they begin to see that delightful person that is inside and all delightful people have aspects of them that, you know, people need to kind of figure out and get around, happens, you know, for you and I as well. So, we just have to think about that. And, at the end I think you need to

understand, get clear in your mind, how does the world benefit from the presence of this person? That's what you want to get clear.

Janet: And you might begin to notice things like, "Wow, she really brings joy at our family gathering. Everyone comes out of their way to give her a hug and get that smile from her." Right? Or, she's a very, very peaceful person. And when you spend a half an hour in the garden with her, just looking at the flowers are feeling the sun on your back, your whole world is distressed, right? And that's a real gift. Or he's got like so much energy can ride a bicycle forever. Well, I just did the ride for heart yesterday. There's all kinds of people who can ride bicycles forever, right? And so, that would be really good. And that kind of energy might be someone who can volunteer at a festival for three days in a row, you know, see if you want to kind of think about that energy in a positive way.

Janet: Or someone who's like a, such an enthusiastic supporter of sports events and it could be his nephew's soccer games or it could be a, you know, the Raptors kind of going into the series, right? So, those are things that you need to share with people. You need to point out because there are things that people can understand with the common things that all kind of humans have in common. And you know, often we need to think about how you can take these gifts are contributions and many of them are at the heartfelt contributions that people, you know, are enthusiastic. They bring joy, they bring kind of a centeredness in a crazy world, but we wrapped them up in more pragmatic ways so that neighbors and friends can get a little closer. So, you know, someone who is joyful around people, they might have an opportunity to bring some baking to neighbors and friends and that kind of thing.

Janet: And the baking isn't really the gift, people think it is. The gift is the presence and the joy of that person. We need to think about contribution. How do people contribute? How do we show the contributions of heart that people have? And so, the idea of getting our head around contribution, I think that's the heart of Rob's story. The minute we understood his contribution wasn't going to be helping kids get their snow suits on, but helping kids to have a positive experience with difference and diversity. We were onto something that everyone understood. The other thing that you can do right away is begin to notice who your son or daughter is at a very young age. We do this for all of our kids, but we are helped to notice the differences and legs and disabilities of our young children more than their achievements or when they glow and whatnot.

Janet: So, we need to kind of spend a whole lot more time on that. And the other thing you need to really start take the time to think about, what are the needs and desires of your neighborhood and friends and other people around? What needs attention? And I think, that's when you might notice, you know, a neighbor out there raking their lawn, they could use a hand doing that or someone's going away for a vacation. Can you, you know, offer to go in and water their plants and pick up their mail? Notice what needs happening and match that with who your son daughter is and how they might like to give. And so, I have a bunch of stories of families who have put these two ideas together, really understanding the gifts and contributions and enthusiasm of their family member and understanding what's out there in community that's just begging to be used or noticed in some way.

Janet: So, I'm thinking just recently I heard the story of a young man who loves gatherings and people coming together and was able to procure just some space at a local community center and put posters around for a potluck. Just thought they'd have a potluck and 25 people showed up, right? So, that's how much people around wants to community. Right? So, that was one idea. More, I know another young woman who loves flowers and would walk around her neighborhood with her mother and noticing flowers and the mother took that extra step and thought, "Hmm, I wonder if she'd like to water the flowers." And so, went to, you know, the neighbor with whom she has the best relationship and says, you know, "Could we come by and water your flowers in the summertime several times?" Now, I don't know a gardener out there that would say, "No, no. Leave all the watering to me." Right?

Janet: So, that's something that she could offer. I know a couple of person who's, a parent helped them to be one of those, there's people who garden little green spaces everywhere or they lead neglected flower gardens. Right? And if you want to see if that is something that your son or daughter might be interested in, it's a wonderful, spontaneous surprise kind of way. And if you do it in your really local neighborhood, people will pay attention. If you're planting flowers around the stop sign or if you're leading a little neglected a corner of the garden. I know a father of a six-year-old, who knows his son just needed to have everything totally lined up in an order and garbage day was just horrendous for him. And so, he, after the garbage trucks had gone by, helped to center some, dragged him out, there and he went up and down the street, lining up, returning all the garbage bins to the home and lining them up perfectly.

Janet: Right. And of course, people noticed that and they noticed that in a very positive way. And so, that little boy is known in such wonderful ways in his community, in his neighborhood. And you know, that's going to go on to do other things. People can be a really good family members to each other. You know, they could be a little sister to a big sister who's gone off to university and you think, well, you know, "What's the best little sister I can be?" You know, can this person be helped to send care packages or email messages or when they come home, can we put something on their pillow? Right. You know, so we can help people. It doesn't take a lot of energy and it's really, really exciting. People can be helped to be the family photographer or family historian.

Janet: And I know someone else who last winter helped bought a snowblower and now, has offered to do driveways in the neighborhood that he lives in. Right? So, that's a contribution as well. Anyways, lots of lots of those ideas and it's by noticing what helps in this neighborhood, what would make a difference and any one of these, you know, afford people a positive identity and opportunity to show their contribution and a way for others to see beyond their disability. It's not that the disability disappears, but other equally or more interesting things are there for people to see and things that they can relate to. So, these are really small acts and you should have small expectations around them. But just doing that makes people feel grand and start to build the idea of a community, a neighborhood.

Janet: And then there's some other ideas where parents had family members had very clear ideas on what their family members should do or needed. One mom, her son was blind and love to hear stories. And she put notes in people's mailboxes saying, I'm looking for someone to

read for my son, maybe once a week. Two people, this is like five years ago, have come forward and they have become really good friends too young Tom. Another person, her son was a 10 or 12 and just learning to ride to a two wheeler for the first time and he needed a whole lot more practice and she found an 18 year old teenager and older teenager who practice and practice and practice with your son till they were riding around the block and riding much more safely.

Janet: And doing so, she found her son a mentor. Right? So, there's lots and lots of examples and I just want to point out again that they, these examples, all still relate to what I said about building a context with relate for relationship. They follow the interests of the person they take place in the best of all places, which is your own street. People are present in a frequent and regular kinds of ways. They have roles as good neighbor, as good sister, brother, family member to play and other people are around. There's always other people involved. And those are the people with whom relationship can really grow. And so, I think that the gist of these from my doorstep kinds of ideas is you're not actually solving any problem, but what you're doing is creating possibility right from your own doorstep, right?

Janet: And so, what you're doing is a huge work. You're putting energy into, a community that is, you know, much better for your son or daughter, but of course much better for absolutely everyone concerned. Now I'm just, I am noticing the time. Let me just say, just a few things about often where people go off the tracks and we want to spend it, you know, think about that. People don't take ...

Genia: Janet?

Janet: Yeah?

Genia: I just want to interrupt you just for a second to say to the audience: if you have questions, now is the time to start adding them into that Q&A box.

Janet: Great. Great. So, what goes wrong is often, people not taking the time to notice, like I said, the interests of their son or daughter. They don't notice if there's any people around with whom a relationship might come. As I said, they might volunteer off to the side with just the supporter. And they don't notice what's happening in their community. Every fundraising is event, every fall festival, every 4-H club event, they have hundreds and hundreds of people doing volunteer roles that are just crying out for people to come forward. So, we need to kind of do that as well. The other thing around interests is that often when we don't follow the interests of the person, it's because we're too busy making sure our own interests. So, you know, the family, they're passionate about something and so, they think their son or daughter should be. The supporter's interests are often the ones that get followed. I get crazy about the number of supporters who have dogs that think that this person should be walking their dog. Right. You know, and of course the person is usually too polite to say no.

Janet: But where is that going? That's what you need to figure out. Where is that going? Who is the person that is going to enter into a relationship? And it's not the paid person. And you know, other people, you know, have lots of ideas of what someone should do with their time. But the other thing is when people have an interest, not everyone follows it in the same way. So,

Rob, with his interest in children in classroom, it is this advocate in one way. There's a young woman named Jade who is the Play Doh mistress. She comes in with her iPad and helps kids make Play Doh and leaves again in her school. And there's another young woman who's the library liaison and she's the liaison between the local library and the kindergarten class. So, similar interest followed in lots of different ways.

Janet: We just have to be creative. The other mistake we often made, and I know this was an early question that came in, is you know, helping page supporters to understand their role. And I think we need to understand that the most important role of a support person is to be a bridge to relationship, not to be the relationship itself. And let me just take a minute to be clear on this is that if a supporter believes that they're going to be this person's friend, you're giving that individual, the person with a disability, a really warped idea of what friendship is. Friendship lasts until the paycheck is gone. And with the best of intentions, that's most of the time what needs to happen. And the other, and it dulls that person's will and desire to kind of have those shaky moments of entering into new friendship.

Janet: For the parents, it makes them think, "Oh good. The friendship gap is filled. And so, you know, I don't have to kind of pushed too much more in friendship." And for the support person themselves, I think, you know, "Gee. I'm the best friend that could ever be, I know this person so well, no one can do it is as good as me." And then the minute the person leaves, there's a huge gap. Right? And so, I ask supporters to think about when I leave, what will I have left behind? Is it a huge gap where people just devastated by me leaving? Or have I lived behind a network of connections and bridges to other people that somebody else can support? And I think that what happens with many page supporters is we don't describe for them a valued role that they can feel proud of because they can play a role that nobody else can play.

Janet: It's very, very valued. And instead we don't give them a role. And so, out of the kindness of their heart, they make up friend, right? So, it's understandable, it's just a huge challenge to get the work done. But when a paid person gets this, they can be fantastic things. So, something to think about. And then sometimes people just get overwhelmed. And what I say often is if you can find two hours a week to create this kind of context for relationship, craft it really, really well and even pay someone to come in and support it. You're sowing seeds that you can just let that sit and work it through and work it through and all the tweaks because it never goes smoothly. You don't have to spend every single day of the week on it and the rest will grow. And then the final thing I just want to say is the lesson that is we have to learn to see the congregation and segregation that is in our world around us.

Janet: Because, let's really be clear that congregation, which is grouping people with disabilities together and segregation, which is setting them apart from all the other regular, typical folks around. It's not a pathway that can bring you to a degree of relationship that we're looking for. So, people get off on those pathways for a whole bunch of reasons. And you know, in the difficulty of life, I can understand that, but for the time you want to dedicate to people being available for the kinds of rich and safeguarding relationship we are talking about, we have to have real places in community that are not congregated by people with disabilities or people with mental health challenges or seniors. Those are the three groups that get put together and elsewhere. I've done just a little chart, which I, Genia, we could share at some point, just

a two or three page kind of outline that says, you know, if you do a week at a glance chart with your family member in mind and think about all of the time that they're in special education classes or day programs or special Olympics or Saturday programs or special church.

Janet: And then all of the time that they're at medical appointments or therapy appointments and all of the time that they're just relaxing at home with the family, how much time is left to grow the kind of relationship that we're looking for. And so, that's what we have to, you know, really think about. Let's carve out some times where we're going to be very serious about this because it's the thing that people worry about the most.

Genia: I find every conversation with Janet to be incredibly valuable. Not only is she perceptive and very well informed about what actually works to improve the lives of people with disabilities, but she's able to really break that down in a way that is understandable and actionable, so incredibly valuable. If you would like to download the chart that Janet mentioned, evaluating how much time your loved one has available for building a context for relationship, you can find that at goodthingsinlife.org/027. It's available for download. If you are interested in attending live interactive presentations with experts on the topic of supporting people with disabilities to have good lives, then check out our events page at goodthingsinlife.org/events. Listen, the bottom line is that relationships and helping people to build relationships are really the foundation of any good life. And so, when we're considering where we put our time and effort in the lives of our loved ones with disabilities, relationship building really needs to be at the top of the list.

Genia: Again, if this is something that you feel like you could use some help with, if attending presentations and asking questions, if getting together with other people who are considering the same issues and have the same goals, if all of that or any of that is valuable to you, then check out the events page at goodthingsinlife.org/events and sign up to get notices. Good Things in Life really aims to help you make a difference in the life of your loved one with a disability. Until next week, take care and I hope you are well and rich in relationship.