

## Noncompliant: A Neurodiversity Podcast-- Transcript

Keenan Wellar from LiveWorkPlay: [Transforming Canada's housing & programs for intellectually disabled Canadians](#)

December 9, 2023

Transcribed by Julie-Ann Lee

[Intro music: Jazzy synth pop music]

**Anne Borden King [host]:** Welcome to Noncompliant, A Neurodiversity Podcast. I'm your host Anne Borden-King. Today we're going to be talking about housing independence, group homes, autonomy and an amazing organization that's working so that more autistic and developmentally disabled people can have their own apartment, rewarding work that pays, and be truly integrated into the community.

Here in Ontario, right in Ottawa, the organization is called [LiveWorkPlay](#) and I'm speaking to its founder **Keenan Wellar**. Keenan Wellar has served as Co-leader and Director of Communications for the charitable organization, LiveWorkPlay since 1997. LiveWorkPlay helps the community welcome and include people with intellectual disabilities and autistic people to live, work and play as valued citizens. The organization has earned numerous accolades including the Ottawa Board of Trade's Best Non-Profit of 2019. Keenan serves as LiveWorkPlay's event host as well as media spokesperson and he currently appears monthly on the Weekly Roundup show on 580 CFRA talk radio.

Welcome to the show Keenan!

**Keenan:** Thanks so much! Great to be here, Anne.

**Anne:** It's great to have you here. And my apologies for my voice, I have a bit of a cold.

Tell me how you got started working in Developmental Services.

**Keenan:** Yes, my origin story of sorts... As a young university student, like so many, I was seeking part time employment and I had some experience working with youth in the community – youth from economically disadvantaged families, and I wandered along what was at the time called the Manpower Centre, and they had an ad to work part time in a program for young people with developmental challenges. I didn't know what that meant. I thought perhaps that meant someone that had an economic disadvantage of some kind... Applied for the job, I was very surprised in the interview they kept asking questions about Down's Syndrome and things. I

had only a vague awareness of this and you know I don't know what to say about this, but I got the job and so I walked in on the first day and literally for the first time in my life, met people... or at least knowingly met people with these labels. And that is how I fell ass-backwards into that role.

And how that affected me was I had this amazing, earth-shattering sort of cognitive dissonance. It didn't happen until hours later, and I realized it was an awakening of what smart people call something like structural ableism. I had no idea what it was. All I knew was, 'Oh my gosh, there are hundreds or thousands of individuals such as those I met tonight who I've just been completely kept away from. I never met a person with Down's Syndrome, or somebody on the spectrum, or anything at all. It just kind of profoundly changed me. I thought, why is this and what am I going to do about it, even as I went along and tried various other things in my young career.

**Anne:** That is quite a story because it is just this visualization of the segregation that we experienced in our society at that time and also still today. So, as you kept working in Developmental Services, at some point in your work you had not only this knowledge and growing awareness but a transformation of perspective in terms of how services should be delivered. Is that right?

**Keenan:** I think we repeated the mistakes that almost everyone that starts such an organization [as LiveWorkPlay] tends to repeat, which is we fell into "program mode". The main reason being if you want funds to actually operate a full-time organization, most every funder wants to fund *programs*, so you start programs. And, before we knew it, we had various congregated-segregated things going on and I don't know how it happened, we just kind of woke up one day and there it was.

We had actually been at a Community Ontario Conference, and we saw **Al Condeluci** speak. He's now a retired professor (from Pittsburgh) who talks about Social Capital, and we had a little, tiny staff team at the time. We had a meeting the next day and I said, "you know, is what we're doing now in any of your views what this is supposed to be about? And we all said "no". And we said, "is anyone here going to leave these programs and go do real things in the community?" And everybody said "no, most of them are going to just stay here." And we all agreed, that is not the purpose of LiveWorkPlay.

So we really just started over, said "how are we going to get this going in the right direction?" and you know, really invested in learning about Person Centred Supports and a social capital of respect and of community based development perspective, and changed everything around, and individualized all of our supports within about... less than two years.

**Anne:** Wow.

**Keenan:** Part of the process was of course, we're still serving those, at the time about 30-40 people and you can't just pull the plug and say, it's all different now. So we did all the things you should do which is, you know, brought in other organizations, family members and individuals with labels to talk about how their life had changed from somewhere else they were in a program structure and then moved to a more authentic life in the community. It took some time. We had said, how about we look at about two years and it didn't take quite that long, which was great. I think it was a learning process. I would also say it was quite typically when families came to us at that time, it was also what they were asking for... they wanted it.

**Anne:** Yeah.

**Keenan:** Basically, specialized group situations. It was pretty hard to envision what else we would do. And also in our own setting here in Ottawa we hadn't seen a lot of other examples, so I guess in our own mind, we're just doing it... "we're doing it better. It's somehow different, like our groups are different somehow". And that was kind of how we fooled ourselves, until we really confronted our own wayward thinking.

**Anne:** Right, and when you changed the program, it seems like you had to do a few things. First of all, you would have to find models and best practices of programs that were doing things differently. So I would imagine that you looked at some models as you built your way along, and did you also consult with people that you were serving and families to kind of understand how to build something new and different that you've built?

**Keenan:** Absolutely, yes and well, so one of our first important partnerships was actually with Community Living Upper Ottawa Valley. It serves the Pembroke area, and we had just discovered that for the most part they had actually made a lot of these changes in the 1980's, so we thought "Wow! You always think something's new, and then it's not, at all", right? So we definitely went up there and got to know them and actually their executive director and one of their board members also came to Ottawa and we had a huge turnout and we had to rent a banquet room, and everybody came and we spoke for hours and hours just answering questions. Talking about their journey and really, and also talking about things that are possible...

I think that's part of your question too...you know, parents would say understandably, "but we tried all those things in the community, and our sons and daughters experienced so much rejection. And we really don't want to introduce them to additional suffering. We like the standard of LiveWorkPlay; we like the environment; it's safe, they have friends." Those were really important conversations and I think that agencies today, they perhaps still considering this

type of change, it would be the same conversation, because families have the same concerns and the same experiences and they're very valid.

It was a matter of learning from places like Community Living Upper Ottawa Valley... well, they didn't just push people out the door and say "good luck". They went and developed relationships in the community to ensure that those spaces knew how to be welcoming and inclusive. So that's the change of job right, for the staff.

A big part of your job now becomes, you go and investigate the types of things people want to engage with, everything from employment to recreation, to the arts. You go and you learn about these venues, and you make sure that it's safe, it's welcoming. That they are going to need some help learning how to welcome this population and you invest in that and you take it right down to the level of the individual.

So one person we're supporting is... their life's ambition is to do photography. Gosh-darn-it, and they haven't had any success connecting with a photography club. We go do the investigative work, and we find the one that's the right fit. You know, is it loud, is it quiet? Is it snobby, is it casual? There's someone we support and they... it's all about the really upper-end equipment and the techniques. The other person is like, no, it's about sharing the experience and fun of photography. Those kinds of things [where] you learn to really dig deep to knowing the person and then matching them to the community venue that's right for them.

[10:20]

**Anne:** Yeah. And it sounds like you're also educating community venues into how to make their spaces more accessible and make them right for the people that you work with and then the next person that comes along, and the next family that comes along, there isn't going to *be* this barrier of the organization, say the photography school just having had no experience, because now they have experience.

It seems like your organization acts as a liaison to other community organizations which allows people to be parts of these activities and then also paves a way for less segregation and more of an integrated approach, and more visibility for developmentally disabled people as well.

**Keenan:** Exactly and again I'm going back to mistakes made. When we were doing that, we used to focus too much on the particular *individual* and their disability, which is first of all very intrusive on that person, but also it doesn't actually have as good of a result for the venue if you make it about the one person. So we've learned really just to talk more broadly. Right, so... Diversity, Equity, Inclusion. Everyone's got a plan somewhere, a policy statement... and so it's a little different now, we can talk about "have you thought about how people with disabilities fit in that, and have you thought specifically about people with intellectual disabilities or autistic persons?" Often, the answer to that last part is no.

**Anne:** Yeah.

**Keenan:** And like, “well, we can help you with that.” And a lot of times they’re like, “okay, that’s great.” And that’s a much better approach than saying like, “Here’s Dennis and all his problems...”

**Anne:** Right!

**Keenan:** It’s not what we thought we were doing, but in essence that’s what we’re doing. And now we’re say, “Hey, this is a cool community. There’s some other people who’d like to join but there could be some barriers for them,” and teach them like how to remove those barriers to make sure this is successful. It’s a much better conversation, one that we’ve used with everyone from housing providers to lawyers, to recreational organizations.

**Anne:** Yeah, it’s happened pretty quickly. How long do you think it’s been since you were initially transitioning to going to speak to organizations and individuals about working with people with intellectual disabilities and just going in totally cold... versus now when you can often go into an organization and talk about concepts like “hey, is neurodiversity part of your Diversity and Equity and Inclusion program?”

**Keenan:** It still feels pretty fresh. But, it’s a little different. For example because we’re in Ottawa we’ve developed a partnership with about 40 federal government departments related to employment. Of course, the Federal Government was quite, quite far ahead on most types of discussions. It was a little bit different than if we’re approaching a family business or something where it’s a good fit for someone we support, but no, they definitely haven’t had that level of conversation. They are often open to it, and there’s kind of that opening where pretty much everybody has had at least some sort of conversation about, you know, just including people facing some level of discrimination.

I think... I don’t know exactly when but I just feel like in the last five years, it’s been a huge shift. We started a lot of this in earnest around 2015, like having things like inclusion workshops and things that were different. **It wasn’t about teaching people about disabilities, it was about teaching people about inclusion.** That was a big shift. I think it was really- it really hit hard about five years ago.

**Anne:** Yeah, that’s been my experience too with [Autistics4Autistics](#). Of course, we were only founded about 5 years ago, but I think we hit the ground right at that moment when, in Canada, when concepts like neurodiversity were really starting to be talked about, even at the corporate

level and things like that. And people were really ready to say “okay we want to have an event, or something to do with, for example, April – Autism Month,” and they wanted to think outside the box and they wanted not to just call Autism Speaks or traditional charities. They wanted to have autistic people come in and represent and talk about what it’s like to be autistic. I would say in Canada it’s really just only in about the past five years, and even in just the past two or three years is when we’re starting to get calls from organizations who want to improve their neurodiversity policy or they’re writing a handbook about this or that... you know the Sexuality Education and Information Centre of Canada for example, they want inclusive language. They want to understand autistic people and developmentally disabled people within that broader framework of diversity. It’s really, really new, and it’s really exciting.

I guess my question that comes off of that though is, what about funding? Has the government funding caught up with the desire of parents and organizations, individuals and groups like yours to really do things in a newer, more inclusive way? Or do you find that there’s a challenge with trying to get funding for non-segregated programs?

**Keenan:** Things are kind of frozen in time. If you look at the Developmental Services budget in Ontario, about 80% of it goes to what you would definitely say is not individualized, community-based outcomes. It goes into congregated, segregated programs and housing. So that leaves 20% for everything else and the everything else includes, you know, like supported independent living, and then that would be like a tiny shred for actually helping people in their daily lives to live an authentic life in community. Yeah, so that percentage has not shifted even if a lot of language around policy documents has shifted. And I guess in a tricky way, a lot of the organizations delivering the services have also adopted the language without changing anything.

**Anne:** Right.

**Keenan:** That’s something new for us. Which is like the same language from our website is replicated somewhere else. Like, honestly, the services could not *be* more different, so that’s challenging.

**Anne:** Yeah. We talk about that in our community as... we call it “neurodiversity lite,” right, where organizations like yours who really broke ground and really came up with new ways and ideas of doing things... It’s exciting! and people want to build off this excitement, but they don’t want to change their model of service. So they adopt the language of inclusive and neurodiversity inclusive programs but they’re *not actually doing any of the inclusive and neurodiversity things*.

And that's like very convenient for funders, because they can feel good about supporting neurodiversity but they don't have to make the paradigm shift. And it's very threatening as well to the neurodiversity and inclusion process because how are we going to do this if it can just be co-opted and something can just be called neurodiversity when it's really still segregated?

**Keenan:** Yeah, that is worrisome. And I mean we're trying to bring focus...

With our partners we actually have a provincial group called **From Presence to Citizenship**, and we're trying to apply some positive pressure around... if this is a change process we're going through, it's not a transformation this time it's being called a *reform process* of developmental services. We really need to focus on what is the change. Like, what do we have now, if it's 80/20 like I'm saying, someone can figure out exactly what it is, like what's our goal? You know if you're setting a goal and having a trajectory and measuring the actual changes the agencies are making. I think we can safely say if they had all congregated programs in housing 10 years ago, and then they still have it, I'm not sure how we can (laughing) if it's the same services that they've changed the language, I'm not sure under what world that counts as a reform or a transformation.

**Anne:** Would there be some way to build accountability into these established service providers, like some sort of a report card or a checklist of how far they are moving in the right direction towards inclusion? I don't know how they would do that report card or accountability because it doesn't seem like there is any legislation that we can turn to, to say "developmentally disabled people do have the right to this or that" because they're often not covered under the types of legislation that you would go to to redress these [disability rights] situations.

It seems like established providers are very... they can be very comfortable in their old way of doing things and there really isn't pressure on them to change things other than pressure from families. And organizations like yours are really deprived of the same level of funding that the larger organizations are given and there does seem to be a bit of entrenchment in Canada, as you mention with your 80% figure. How do we work our way out of that?

[20:10]

**Keenan:** Well, in my experience, I think government in general would like to say it's someone else's responsibility (laughingly), but I think as it is taxpayers' dollars that is going to the government, which is then going to the delivery of the services, so in every other aspect there are principles associated with these things. In the health sector we don't just say "oh yeah, you just take your health dollars and just go anywhere, it's fine and we're not worried about the outcomes...just tell us how many people you're serving, and for how many hours."

**Anne:** Right.

**Keenan:** We don't do that.

**Anne:** Yeah.

**Keenan:** So that's kind of still what's going on here, but we are... it's a great question you asked because we are still in the early stages of a new policy framework called Journey to Belonging in Ontario and there's not a lot of answers yet about what it *means*, but many of us feel that we're right in a kind of a fresh battle over...does inclusion just mean anything that someone chooses as long as they feel it's inclusion or their family feels its inclusion or are there principles or are there principles basically principles we have to follow, that in accordance with our own Charter of Rights, the United Nations' Convention on the Rights of Persons with Disabilities, other human rights? Just where we've been going since the 1950s...

**Anne:** Yeah.

**Keenan:** Does any of that matter as de-institutionalization, because there's also this dialogue of individualization which is very positive in many respects. We want people to have individualized supports and services, but in recent documents the word *choice* appears a lot, and it seems to be...as someone a little bit rusty, but I did my Masters in Applied Linguistics, and I pay attention to what's showing up in this document... they're using that word *choice* a lot. Why are they doing that?

Well, potentially it's saying that as long as the individual and/ or their family is making that choice then it's not for us to say that it's the wrong choice. And this is potentially a path to back-sliding into congregated services for a little bit of a trap on that. because we had the sort of 80/20 resource discussion, and so I think those families are making a fairly logical decision because that program is *something*, it's got a structure, they feel they can count on it, and it's definitely better than nothing. And I mean, that's their primary concern. It's very complicated to ask... you can't just go into a sheltered workshop and ask the person, "hey, do you like it here?" And, "Yep." "Okay, well, I guess we've done this survey, they all like it here." And that's what happens a lot..."I guess it's effective, [we] have done surveys like that of every kind of congregative setting," right?

**Anne:** Yeah.

**Keenan:** "They say 100% of people love it here."

**Anne:** Right...



**Keenan:** And then you go, "...and the viable alternative they were offered and experienced was?" "Oh, nothing."

They've never had an alternative experience, or been offered one, or had a chance to see what it would be like. You know, we learned that first hand, right? So we did our own... when we were running our own day program we got "100%, A+, love it". The difference is, years later you ask the same people "So would you want to go back to the SMILE program?" Well, "no, of course not".

I mean, this is the challenge. How do you ask these questions in a way that's fair? You can't ask people when the choice isn't there. You don't get correct information. at the same time, it's hard to offer them the alternative because funding is still locked into segregated [programs].

**Anne:** Yes, and let's talk about that in a moment. I want to switch a little bit of gears to talk about this really important concept of "better than nothing" which I sometimes refer to it as the "loneliness surtax," because families and people with intellectual disabilities or autism experience a great deal of loneliness and end up kind of putting up with or sometimes paying exorbitant amounts of money for really sub-par programs and segregated programs and things like that simply because it's better than nothing.

And now we have to look really and say, well there is something *better* than "better than nothing", and what does that look like? Well, what that looks like, I think, is what LiveWorkPlay is doing. I wonder if you could give a couple examples of the types of programs that you do... Maybe we could talk a little bit about housing as well as well as work, and recreation... Living, working and playing. Could you give a few examples of successful projects that you've been engaged with in terms of making those connections, so that people can really see what looks better than "better than nothing"?

**Keenan:** Sure, I'll try. That's a really big question, but...I'll start with housing, I think cause that's a really interesting journey. so we did some of our own dabbling in housing and again [there were] mistakes and lessons learned, so we were just concerned that, you know, there wasn't enough supported affordable housing, so we actually applied to the Canada Ontario Affordable Housing Program and we owned seven units of our own for a while, and realized yeah, no, we're not in the business of being a landlord.

**Anne:** Mmm.

**Keenan:** And we're terrible at it. So we got out of that. Sold the units actually to individuals and their families, which is great, it all worked out. But, then we figured out one of our best partnerships is with the non-profit housing community, which is not the same as... it often gets

confused with social housing...So non-profit housing is just a formula where you have people paying from market rent to subsidized rent and below market rent and in between. Then you have a formula, and it all works out and you can pay the bills but you have this... you have a community that's diverse – financially diverse, economically diverse. But then often they choose to be diverse in other ways.

We work with three of those in Ottawa, Multifaith Housing Initiative, Nepean Housing, and Centretown Citizens Ottawa. They're all non-profit providers. They're each a little different, but it's been wonderful. For people who want that, it's a bit more a sense of community with some variations between those three things, but it's been just life changing, I would say, for those who have chosen to live in those communities. The affordability factor, but also the opportunities to engage with others who live there, and not as a group of people with disabilities, just as other tenants or other people who live there.

That's been really cool, but we also have people who do not want that at all...they would like to live in just regular housing of any kind and just keep to themselves, and that's also just fine. We learn to support people's individual needs, but I think that the non-profit housing has been great.

You talked about the loneliness issue, and that's a big one for housing because there's a kind of a perception of being around other people... like having that baked into your living situation, somehow means you *aren't lonely*.

**Anne:** Yeah.

**Keenan:** Right? "Well, if you're in a group home, how could you be lonely, there's people around you all the time?" And, that's a different thing, like being in the same room as other people isn't the same as like having relationships, feeling good about yourself, having reciprocity, and all those sorts of things.

My favourite story is I was contacted by one family who was trying to help another family who was concerned that their daughter would not do well in her own apartment because she would be lonely. And I met them through the Down Syndrome Association. I knew this young man, he's quite public about this, so I'll just say his first name is Daniel, and I said "Daniel... a bit of a weird request. I would like to visit you with two parents, who are trying to make a decision about housing for their daughter, and just have a conversation. I don't want to tell you anything more than that. Is that okay? I know it's strange." He's like, "Yeah, sure." So we come over... he's got his nice place ah at Multifaith Housing Initiative, he's prepared coffee and snacks, they come in, they sit down. They start talking and he's telling them about his apartment and his life, and they get around to, "But isn't it lonely? There's nobody else here with you."

And he puts his hands to his head and he looks like he's going to cry and I thought "uh oh... this isn't going in the direction I wanted." And then he goes... "Let me tell you my biggest problem. My friends keep coming over unannounced!...I need some time for myself. I'm exhausted! You know, I figured out, you just tell them 'let's go out, we want to spend time together, you know we're around our apartments enough. Let's make appointments, and let's go downtown and do things.'"

And, just the change in their face when they realized, okay, it's not a problem. He actually has *too much* going on in his life and needs a break. That's my housing story.

[30:13]

**Keenan:** I think in the recreational area we've had some really great experiences. New sports organizations... a lot of them are starting up in communities all over the place, but a lot of them have a focus on "we just want people to enjoy sports", and so they're kind of inclusive from the beginning.

We found that people who had previously, they would have been thought of as perhaps like Special Olympics being maybe their only option if they wanted to enjoy sports with others, and now, you know [there are groups] like Ottawa Rec Sports in Ottawa, where their mission is everybody can enjoy sports together. I remember we thought we'd have to go in there and do a whole big presentation and convince them like to let our people in and they were just kind of like patiently waiting to tell us, "yeah, you don't need to do that".

**Anne:** Ahh, that's nice.

**Keenan:** "...Just explain like anything we need to know, and things we might need to do differently." And the cool thing about that is one of the keys to knowing if someone is really included is, are they at the afterparty of these games? Like, after the soccer game, are they at the bar?

**Anne:** Yeah.

**Keenan:** Do they have a ride home? Like, have people thought these things through?

**Anne:** This relates back to this concept of the **Burrito Test**. The Burrito test, as some people know, is the question that you ask as to whether someone has autonomy in their housing. Can you get up at 11:30 at night, and you're hungry and microwave yourself a burrito? Or, is the fridge locked, and you're not supposed to go in the kitchen, and you have to be in your room? That's the Burrito Test, in terms of how, whether-or-not someone has autonomy.

Autonomy is so important to quality of life because everybody wants to be able to get up and make themselves something to eat at night if they want to. And it's just symbolic of the many types of freedoms [and] that just because people are congregated together, like you said, doesn't mean that they're not lonely... doesn't mean if you have to ask permission and to do things in a certain way and go out in a certain way and only do certain types of activities versus being at home in your house like the man that you mentioned and being able to have the freedom to have friends over, or not have friends over, or go out with friends.

These are things that we have seen in model programs where if people have enough supports, you know just the right amount of support coming into their apartment, they can have an apartment of their own. Or they can have an apartment with a roommate, but choose the roommate. And choose their support worker and choose what they do. And that's what the concept of autonomy is, but so lacking in much of the Canadian investment in housing in our sector.

I guess you're right now advocating for more support for programs like yours. What direction do you think it's heading in? Do you think we're heading to a place where more and more people are going to be able to achieve the Burrito Test and have that kind of autonomy? Where are things headed in terms of housing and also recreation like you were talking about?

**Keenan:** I'm really worried about where things are going with housing. We're in definitely this affordable housing crisis, right? And one of the consequences of that is if someone wants to create housing the funding mechanisms for that tend to be focused around these big projects. If we're building 100 new housing developments in Ottawa, then how about, "you know 5% people with intellectual disabilities or autistic persons in all of those units, and it would add up to this many and that would be great." It doesn't work like that typically. Those sorts of programs, one building with 40 people in it and you have some kind of a label.

And you know it's really hard to break free from that and it also can be used against advocates, so I've certainly had my own experiences of people saying, "Come on, Keenan, there's not enough housing... any housing you can get, you need to get behind it." Like, you know "Stop putting a pin in the balloon, stop dream-crushing here, because of your own particular views on housing. We don't have enough period, so you do your thing, we'll do ours... There's this big thing over here- you don't like it. But, some people like it just fine, and so what's the problem?"

That's a really challenging dialogue especially when it tends to be agencies that can afford lobbyists and really good communications and lawyers and they've lined it up and they've got the testimonials, and the research group has done the survey, and "everyone loves it," and why not? So there's economies of scale, like there's all these things that line up and you're just kind of stuttering going, "but, but... *what about their lives?*"

**Anne:** Yeah.

**Keenan:** It's very challenging. We're trying to find lots of different allies on that too, and people with lived experience are the best at that. That makes me so happy to see this, you were talking about the voices of Actually Autistic persons. I think, you know smart... smart people and also even self-serving people that have responsibility for that sort of thing are starting to realize, it would be a lot better to just ask members of that community and have them speak to this.

I mean, I just came to this from the Disability and Work in Canada Conference last week and it was so great to see... It was such an expected thing in every session there were voices of different people from marginalized or vulnerable communities speaking for themselves and sharing experiences. It changes the whole dynamic and we need more of that. It's just really hard to develop as you know it's not that easy for people with intellectual disabilities or autistic persons to find their voice. It often takes a lot of support to get there, as well as the invitation.

**Anne:** Mm-hmm.

**Keenan:** I think really, really critical. Certainly, you know Autistics For Autistics and voices like that, that's really changed... even just putting people on notice, like you're not going to get away with saying something on behalf of the community when they haven't been asked what they think. I think even the awareness that there are voices that exist, it helps change and at that ability to manipulate public statements.

**Anne:** It's very incremental, because we're at the point now in the autistic community, I think somewhat also in the Down's Syndrome community, I think in the generally intellectual disability, it hasn't come quite as far and we need to be lifting as we climb. But in the autistic community, we're now being asked to consult with governments about policy.

The problem is we show up and they say, tell us your story, and then people pour their heart out and they really tell their story. They're also telling *in* their story their idea for how things can be better and the idea is- is across the board is to be able to afford and have one's own apartment, and live independently, sometimes with supports. Be able to have meaningful work, be able to have meaningful recreation, and just for the government to help make that possible for people. That is the message that's really clearly been said in all of our federal consultations and some provincial consultations.

The problem is once they've heard "the story" that people told... people told their stories, some people in policy just tick the box off and say, "yeah, we listened." Right? "I did the thing, I listened," but they don't act on the input that was given when people poured their hearts out and told their stories.

And so there is a sense of betrayal, I think when people go there and really talk about “hey, I don’t want to live in a group home, I don’t want to live in my parent’s home, I want to live on my own and this is what I want.” And, then to share that with policymakers but not to see it actually get translated into policy again feels like an experience of neurodiversity lite.

**Keenan:** It’s also a respect issue. It’s all good and fine for Keenan to say, “yes, all these labelled people should show up and share their stories and put all their time into free advocacy work, because of course, they must be getting free rent somewhere. They don’t need to have jobs, or you know they could just spend all their time telling their stories and going to conferences.” Meanwhile the consultants from the high-priced consulting firms are not doing that, right?

**Anne:** Mm-hmm.

**Keenan:** They’re actually getting paid to host the consultation, and gathering all the free information... they may or may not choose to use it, as you say. That’s been bothering me a bit lately. I’ve been trying to kind of sort through that. I’ve been kind of accused of being the smart-ass about that, but I was actually trying to make a valid point to government which is I guess, probably there’s a valid use for hiring KPMG to sort of co-ordinate information in a professional way, but at the same time, I think we should respect whether it’s organizations or individuals that are bringing expertise to these issues, I think we need to respect them more than just *inviting* them to a consultation.

[40:22]

**Anne:** Yeah.

**Keenan:** I think perhaps what they have to say or what they know is actually *more* valuable than sometimes what the MBA consultants have to say.

We have this own experience with LiveWorkPlay. we have very passionate supporters of the organization who say nice things about the benefit to them with finding housing or jobs or things. But not a lot of them actually *want to* go around consulting about their lives.

**Anne:** Yeah.

**Keenan:** It’s not for everybody. They actually want to spend time with their significant other and go to movies, and they don’t necessarily want to go around conferences and play a self-advocacy role. It’s not for everybody. And so it’s challenging because I think their voices are critical but, not everybody is just going to take time out of their day to do that, especially when

as you say, what are the tangible results going to be if I open my heart, and open some wounds, right? It's asking a lot of people to expose the... you know, a lot of trauma. That's what we're talking about...

**Anne:** Yeah.

**Keenan:** It's very traumatic going through these barriers and disappointments and sometimes you know quite severe abuses.

**Anne:** Yeah.

**Keenan:** And so being asked to do all that is not exactly what most of us envision our spare time. I think it's really tough. And so there's still going to be... there's going to be a role for agencies, and they have to challenge themselves to really represent that voice with accuracy and honesty.

**Anne:** When you created the change in your organization, you can see and must be gratified every day to see that people's lives are more satisfying. Their quality of life has improved because of the service that you're providing. But, you've said previously as well that you know delivering these services is actually *the means to the end* for people enjoying their rights. And, you know, you said that you rather people just *have homes and jobs and social lives in a world where there wouldn't even need to be a group like LiveWorkPlay*. Could you say a little bit more about that?

**Keenan:** I mean, that's kind of the goal now. I mean, you mentioned "just enough support" previously. That's a concept we believe in, so people's need for support shifts and changes, and sometimes reduces or vanishes. But for a lot of people it continues, but it can change, so the way we are supporting someone who moves to a home of their own for the first time in terms of their, you know, their meal planning and shopping and all those kinds of things, we're always challenging ourselves like... maybe we're doing almost all of it in the beginning...[but] the goal is to get out of the way as much as we can. At the person's own pace, of course.

Ultimately, we would like to work ourselves out of that role, so that yeah, "I can shop on my own and I can make my own meals." For some people that's very realistic. For others maybe it's partially realistic, but it's doing the best we can to help people move in a more autonomous direction and take more control over their lives...you know, their banking and things like that.

We encounter so many people, like the level of powerlessness over so much of their lives, it's almost hard to imagine and I guess we get so used to seeing it and sometimes I have to remind

myself, what must that be like? You know, someone is presenting to us for the first time with their family at an initial sort of a planning meeting or call that an intake meeting and you're getting a sense that this person has virtually nothing in their life that's in their control. How are we going to take some baby steps to get them a little more control and autonomy which hopefully as they demonstrate their success with that it will open doors and they can do more and more. That's kind of always the goal...That's already our goal...

People might need some help with different aspects of living in their own home. They might need some home care, or things like that, but you know we want to make ourselves fade as much as we possibly can in the individual sense, but then also in the societal sense over time. I feel like we've come a long way as... I feel really good about what we're doing right now, but hopefully, you know I really do hope that 10 years from now there's some looking back and going "oh man, I can't believe we were..."

**Anne:** Hmm.

**Keenan:** There's always room to figure something out a little better and I would say what are the things we're still struggling with... how do you support social lives? We still host and support meet ups on Friday nights in various places across the city, and we can't quite figure out... there's some artificiality to that, but without it, people are saying "well, I just won't go out." And like, how are we going to navigate this? So we don't have an answer yet. That's an example.

I'm hoping 10 years from now, I have something different to say, because we haven't sorted that out. We got it to the best place we can figure right now, but there's got to be something better and I think ultimately it's that the community changes to the point where that type of intervention becomes unnecessary. Like, our people we're supporting just have better success with the mainstream meet ups, movement and groups. And they're able to succeed there in ways that's not working.

**Anne:** That's such a good way of putting it. There's still a lot to be sorted, right? In terms of we're not living in the perfect society that people and organizations like yours have the vision for. And it's so important to have that vision because it eventually gets you there through like you said, these baby steps.

The vision is there, but there's the day-to-day reality as well, and there's balancing all of that.

I talked in the [last podcast](#) with Andrew Whitehouse from the University of Western Australia about this concept of service providers and researchers approaching everything with a sort of humility. Humility in terms of understanding new ways of thinking about things, which you've demonstrated so much over decades of your work. And also, you know, a humility to



understand the systems within which we're working and we're trying to find compromises and then really hearing what people have to say about what they need and then placing that up against the vision itself.

Let's say looking back on 2023, what's really jumped out at you?

**Keenan:** It's gotta be kind of a tie, because there's still nothing like the moments of celebration, there's nothing like the moment the person that gets their first job. I think it's just so concrete, and I hope the way we're doing it means it's always about people getting authentic employment where they're valued and they know it. I think there's a light in the eyes with that, and that particular moment still thrills me. It happened this week, actually it wasn't someone's first job but they had had a job for a long time and lost it, and just got a new job and wow! Like the beam in the eye and just the flood of support and celebration of that person's journey.

But I think that those smaller things of people finding a place in the community.... We had a gentleman that found a walking club which has been a bit of a struggle. He likes to walk and we've been trying to find where his people are for doing that with others, cause he also wants to socialize and found that his community... they do it all winter too. They have an indoor version. Amazing! Like at least once a week and just to see the photos, like he's next to people with their walking sticks and they're all ages and they're [conversing] and he's telling the stories of as they walk they talk and it's just amazing.

And you think more about the... if they didn't have that, if that didn't happen.... how their life is different. It's only like, it's once a week, but it makes a huge difference in that person's life. It's just every day, I have to say there's still these thrills and it happens so much sometimes I actually, like I'll find out, like "what, I didn't know that happened!" which is great.

I love the fact that essentially, we're overwhelmed with those small good news stories. They go along with the bigger ones. Like people getting their first key to an apartment. It is no different to anybody. That is exciting for all of us! Like you open the door and you close it and wow! I can only imagine it's even more so for someone that maybe thought that would never happen for them. If you can imagine thinking "I'll never have that experience like my brother and sister have it, but it's never gonna happen for me" and then they get that experience. I can't even imagine how fast their heart is beating and what they're thinking.

[50:16]

**Anne:** Wow... It's amazing work that your organization is doing. I want to thank you so much for being on the podcast, and let listeners know as well, for those who want to know more about LiveWorkPlay, you can visit them online at [LiveWorkPlay.ca](https://www.liveworkplay.ca). You can follow them on twitter @LiveWorkPlay and you can also find LiveWorkPlay on [Facebook](https://www.facebook.com/liveworkplay), which is a great page, LiveWorkPlay. Thank you again for being on the podcast, and for all that you do, Keenan.

**Keenan:** Wow. Thank you so much for your kind words.

**Anne:** We were just speaking with Keenan Wellar from LiveWorkPlay. He spoke with us from Ottawa.

[Outro music: Jazzy synth pop music]

**Anne:** You're listening to Noncompliant: a Neurodiversity Podcast. I'm your host Anne Borden King. Noncompliant is recorded at MCS Studios and transcribed by Julie-Ann Lee. This episode was engineered by Lucien Lozon. Thanks to our team and thanks for listening.