

Episode 11 - P2B

📅 Wed, May 24, 2023 12:24PM ⌚ 40:59

SUMMARY KEYWORDS

research, belonging, team, project, inclusive, young adults, disabilities, infographics, rebecca, zoe, team members, involved, participants, pathways, ideas, voices, thought, important, perspectives, jen

SPEAKERS

Zoe, Francis, Jasmine, Jen, Rebecca

F Francis 00:14

Hello and welcome back to another episode of the rehabINK podcast. My name is Francis, and I'm a graduate student at the University of Toronto's Rehabilitation Sciences Institute, and a research assistant part of an inclusive research team and project called Pathways to Belonging, or P2B. Today, I'm joined by four members of the Pathways to Belonging team, and we will discuss what exactly inclusive research is.

F Francis 00:40

Thank you all for joining me today and taking time to share your experiences and chat about the P2B project. Just to start off for our listeners, can you each introduce yourself and your role in the Pathways to Belonging project?

R Rebecca 00:56

My name is Rebecca, and I'm a professor in the Department of Occupational Science and Occupational Therapy, as well as the Rehabilitation Sciences Institute at the University of Toronto. My education and training are in social psychology and occupational therapy. And I'll just say a bit about my research. My big, overarching research question or the area is on belonging as well as meaningful engagement and participation in community life and society for disabled people, in particular people with intellectual and developmental disabilities. My current research focuses on belonging and engagement and participation in a meaningful way in community life and society for people with disabilities, in particular, people with intellectual and developmental disabilities.

R Rebecca 01:49

The P2B project focuses on young adults with intellectual and developmental disabilities who are between 18 and 35 years old. And really, the purpose of the research is to find out from

them how belonging happens or not. And we also asked the same question, or examined the same question, for other people who are important supporters of young adults with intellectual and developmental disabilities who are their family members. They were also participants in the study. Service providers who are paid and work in formal organizations and also people who work in voluntary organizations. This research addresses that question that I just mentioned, through in depth-interviews with young adults themselves, their family members, and paid and volunteer service providers.

R

Rebecca 02:45

The study though, I want to stress, foregrounds the perspectives of the young adults. And it includes the perspectives of the other two groups of participants, the family members and the service providers, because we want to understand through analysis, how each of those groups- and this will be a separate analysis for each group - how their perspectives on how belonging happens could be described and characterized. And then we want to put together that information from each of the three groups to try to integrate and sew it together.

R

Rebecca 03:18

And the reason we want to do that is to see where there are areas of agreement on how members of the three groups of participants see belonging happen and how they see belonging happening or not happening. And what kinds of supports and resources might help belonging happen for more people, more often. So, there may be points where there's lots of agreements, but there may be points or issues where there are very different opinions coming from the same group as a whole. And sometimes maybe there are some, what I might call points of tension. That is when each of the three groups kind of almost seems to be thinking and working across purposes to make belonging and happening. So what young adults might think is important in making belonging happen for them might be quite different than what parents think will be helpful or service providers think will be helpful. So it'd be really important to highlight that so that it can help inform programs and policies about these different points of view, and maybe how to work with those different points of view, so that maybe they can come together in a different way to really support belonging for young adults.

J

Jasmine 04:39

My name is Jasmine and I'm a school occupational therapist who's currently working in the San Jose area of California. I've been involved with the Pathways to Belonging project as interim research coordinator, videographer, interviewer, and as a research assistant.

J

Jen 04:57

My name is Jen and I'm the project coordinator for the Pathways to Belonging project. I'm an occupational therapist and I've worked in different settings with different people, including young adults with disabilities, but after one or two years being in clinical practice, I started working full time in research and fell in love with it. Now I'm here, and as for my role, I see

myself as the person connecting everyone together and keeping the project moving and on track, making sure that everyone on the team is informed and involved in every stage of the research.

Z Zoe 05:29

So, my name is Zoe, and I'm a project consultant on the Pathways to Belonging project. So my role is to make sure that the language that we're using on different pieces of the project are, like, that people with IDD can understand them and understandable. And to make sure that there's some lived experience on the research team with people with IDD.

F Francis 05:57

Thanks for that fantastic introduction, everyone. And I'll just point out to our listeners, I think everyone's voices are quite different, but I do want to emphasize that Rebecca, Jasmine, Jen, and Zoe we will be speaking in this order for the rest of the episode, just to hopefully make it easier for everyone to follow along.

F Francis 06:17

So, this leads me into my next question of how did each of you become involved with the P2B project?

R Rebecca 06:25

I was the lead researcher on a previous project called the Voices of Youths project that developed a theoretical model of belonging for teens and young adults with intellectual and developmental disabilities. This model was developed out of interviews that we did with teens and young adults with intellectual and developmental disabilities and their friends about their own perspectives on what belonging meant to them. This project showed important, interconnected aspects of belonging, but it did not show us how belonging happened or not. So, my colleagues and I took another step forward and applied for funding from the Social Sciences and Humanities Research Council of Canada to do the P2B research, and to examine the question or try to answer the question of how young adults come to feel that they belong or don't belong in their community and in society.

J Jasmine 07:24

I was also involved with the Voices of Youths project, as Rebecca was saying might be the prequel to the Pathways to Belonging project. I remained involved with the research, and I'm now here on Pathways to Belonging.

J Jen 07:40

I was not involved with Voices of Youths, but I learned about the project from Rebecca and was very impressed and interested after hearing about it from her. The timing was just perfect, because it was at a time when I was transitioning from a full time to a part time coordinator role, so I had capacity to take on additional roles. And I've been working with a team for two years and I still can't believe it's been that long.

Z

Zoe 08:02

I was also part of the Voices of Youths project. And I was also a project consultant on that. And then I got asked to be part of Pathways to Belonging.

F

Francis 08:14

So given that you all have different roles on the team, and it sounds like different experiences with the Voices of Youths project which happened right before the Pathways to Belonging project, I'm wondering if you could talk a little bit more about your individual experiences. Maybe you could share some accomplishments and challenges you've experienced?

R

Rebecca 08:36

I'd have to say, Francis, that my experience has been very positive and very exciting, but at the same time, very challenging. And I'll try to give some examples about why I'm saying that. It's very positive for me, because I'm able to work with some research team members from Voices of Youths, like Zoe and Jasmine. I'm also able to work with some new team members, as well as the P2B team as a whole. So that was a wonderful opportunity for me and I have really enjoyed that. Our team includes young adults with intellectual and developmental disabilities, family members and service providers, as well as our research coordinator, Jen, other researchers and research students, and research assistants. So it's really exciting to work with people fulfilling those different roles and it's exciting to see how everything comes together when everybody's involved in collaborating within these various roles, as it's been very rewarding to develop relationships, as I said, with individual team members, but also with the team as a whole because I sort of feel like our team kind of has its own personality, which I enjoy very much! Although I've done inclusive research on previous projects with other teams working with each different team has provided opportunities for me to develop new research skills and strengthen ones they already had, especially communication and collaboration skills.

R

Rebecca 09:59

On the other hand, it's been kind of challenging because as a researcher. I often and even routinely use technical and academic terms and in inclusive projects like P2B, communication has to be accessible for every team member. And not all team members, of course, have research background and experience. They may have been on a research team before, but they don't necessarily know all these expressions and jargon, nor is there any reason for them to know those expressions. I have to really remind myself all the time, even though I really want to, but sometimes I slip. And I have to really concentrate on using clear, plain language, trying to avoid short forms and acronyms, or explain what they mean. And always do this and

plain, clear language. And sometimes it's a little bit challenging, because if I'm trying to explain something complicated and complex that I have a name for, like the name of the theory or something, I have to really think about that. And it's very hard work and I do enjoy challenging myself, and I do enjoy being able to do that eventually, and feeling that I've accomplished something. But I also want to check it out with the group because I want to make sure that they also can understand what I'm saying, and that I'm not just thinking I'm saying it clearly. It's worth all the effort to understand what is being said, and hopefully facilitate understanding through others. Because if we don't do that, I think it excludes people from the research process, if you don't use the language that everyone does, or what I wanted to want to get out there.

J Jasmine 11:30

I feel like it's really changed even my philosophy on how I approach everything from, you know, my political engagement to the work I do as an occupational therapist. I'm explaining this as a little bit more of a philosophical experience than as my actual personal experience. So I just want to preface with that. It's really reoriented my perspective on what it means to do meaningful research. I'm hoping that our research aims to inform social, economic and health policy, and the production of knowledge about disability, and its impact on community belonging, and quality of life. That has to always begin and end by centering the perspectives of the people it effects the most, which for our purposes, for our research, is youth with disabilities.

J Jen 12:19

It has been an incredible experience working with an inclusive research team. There's a lot that we don't know as researchers working in academic setting. And for me, it's just wonderful to have what we know be enriched by the experiences and knowledge of our project consultants. For example, in a meeting, we would be sharing let's say, some emerging findings from our analysis with our team. And they will point out something that is completely unknown to us. And we get those moments where we just go, "Oh, I never thought about it like that." And then more and more important ideas come out of those discussions. It's amazing!

Z Zoe 12:57

My overall experience has been, like, a good one. I think, as a team, like, we get along well, and we have like a close bond with each other. It's important to share these experiences, because at the end of the day, they really do matter.

F Francis 13:20

I feel like all of these questions have been building up to this main question of what is inclusive research or how would you describe inclusive research?

R Rebecca 13:35

Well, typically, inclusive research includes people with disabilities, but it aims to do the research with people with disabilities as community partners, rather than doing research about them without them being active members of the research team, as has often been done in much of the research that's focused on people with intellectual and developmental disabilities. And that's especially true in North America. This kind of inclusive of research has been done a lot in Australia and the United Kingdom. So, the reason for doing research inclusively and having people with disabilities being part of the research team, is that there's lots of differences in power between the people that are doing the research and the people whose lives are being researched, especially when you use a traditional approach to research. Inclusive research tries to level that playing field a bit. It's not perfect, but it really attempts to get rid of those power differences, so that the people who are influencing what gets asked in a research, let's say in a research interview, and what becomes the focus of the research and how the research is done, is really collaboration between researchers and community members, including, and including most importantly, people with disabilities themselves. So that's kind of my understanding.

R

Rebecca 15:06

I kind of base a lot of the inclusive work that I'm doing right now on some published literature, and I'll just sort of mention Frankena and her colleagues, and Nind and colleagues, who have set out some, I think, what are some important principles and ideas about inclusive research that try to describe what the characteristics are. So maybe I could just say what I think are some important characteristics. And this is based on the work of the researchers that I just mentioned. The research topic and the research purpose must be of great interest to people with disabilities themselves. Also, people with disabilities are acknowledged by the researchers in the research team and respected as lived experience experts, which I think Zoe has already mentioned in some of the things that she has said already. People with disabilities are actively meaningfully involved in contribute to the research process, including making decisions about the research, especially the major aspects of the research throughout the life of the project. And I keep using that term active because I want to stress is that this is not about tokenism, or just having the presence of people with disabilities on the research team, they are truly members of the research team.

R

Rebecca 16:30

Lots of times our project consultants or young adults with disabilities on the team have pointed out things during our presentation of how the analysis is coming along so far in the research meeting. And when we try to get feedback from the group, we get some very surprising and insightful things from the young adults themselves. And our research wouldn't be nearly as meaningful. And so if we didn't have the benefit of the participation of those young adults who are lived experience experts, I think the research would turn out very differently without their input.

R

Rebecca 17:07

These are some ways that in my mind, and in the mind of the researchers I mentioned before, that should be built in to the inclusive research process. Communication and ways of working

with an inclusive research team need to be tailored to be accessible and understandable to all team members. And this happens, for example, through the use of accessible materials, accessible plain language communications, during and outside of regular team meetings. And I mentioned earlier that without inclusive language and without those materials and communications that are accessible to all, you can't have people feeling like they belong to the research team unless they are included in those respects, through communication, through assessable materials, through language.

R

Rebecca 18:04

And finally, I would say on inclusive research that the outcomes have to have strong potential to help address an issue that is really important to people with intellectual and developmental disabilities, at least in the case of our own project, because that is the group whose lives we're interested in learning more about. And the outcomes of the research, the findings, for example, have to have lasting benefits for people with intellectual and developmental disabilities who are involved in the research themselves. So for example, we want our project consultants to learn and/or enhance some of their research-related and interpersonal skills, as other people on the team are able to quite often do. We want them to have many opportunities to do that too, just like any other team member. So if it doesn't, if the research doesn't have those benefits, then the inclusive part isn't as good as it could be.

J

Jasmine 19:03

Inclusive research means that the Pathways to Belonging project actively involves people who we hope to engage in our research beyond just asking them to be our participants. Instead, we aim to integrate their perspectives into every aspect of our research from the original research questions and topic, and all the way through to knowledge translation methods. Not just listening to them as participants but actually in shaping the questions and the underlying assumptions as well.

Z

Zoe 19:34

So, our project is unique because project consultants with lived experience are on our team. And they are trying to create the lives that they want in a world that may not be, feel safe, feel safe for them. Because we're using the services that they might want to improve, and plus, the research team will ask us, what language. So, like, using like, if we're using language that may not be inclusive that um, make it more understandable for, so individuals with IDD could understand them. And this could vary of what we're working on, on what stage of the project we are on. And what kind of things really we working on, like the infographics and, and that type of thing.

F

Francis 20:37

I know Jasmine, Rebecca, and Zoe - you all kind of touched on this in different ways. But, more specifically, how is inclusive research different from other kinds of research?

R

Rebecca 20:52

I would say it has a number of differences, I'll just try to summarize what I think are some key ones. And, and some of this might repeat what I said a bit earlier, but I do think they're worth emphasizing. So first of all, it's different in that it carries out research with people with disabilities, whereas more traditional research approaches do research about people with disabilities. I guess inclusive research embodies the slogan "Nothing about us without us," because most research is about people with disabilities, and leaves them out as part of those who are shaping the research process, and therefore determining what kind of questions get answered.

R

Rebecca 21:39

Our lived experience experts did so many things from collaborating on the design of our website and making decisions about what it would look like and what would be on there, to collaborating to develop what actual research questions would be asked to our participants and the language that will be used, because I remember distinctly Zoe saying, "You know what, you can't ask it that way. You have to say it this way." Or you have, you know, I remember Zoe - this might be from earlier - you said, "You know, we don't want to be called youth. We want to be called teens and young adults. So don't call us youths." And that really stuck with me. I thought, "Wow, okay, that's really important. Why didn't I think of that?" But you thought of it, so that's great! And you joined us! And that was really helpful to asking questions that would be better received, I think, by the people that we were interviewing.

R

Rebecca 22:42

The other thing that I want to emphasize is that clear, plain, accessible language is used in communications, in meetings, by all team members and all materials that are used by team members. And I know I've said that before, but I want to emphasize it because I don't think this always happens in research teams. It's not something that people are paying attention to in more traditional teams. But it also differs from participatory action research, which is also a very common form of research that involves people with disabilities on a research team. The difference between inclusive research and participatory action research is that inclusive research does not aim to actually produce a resulting program, or some other specific form of active social change as part of the research. So although our inclusive research helps to inform and influence programming that others develop for young adults with disabilities, or government policies that get developed for young adults, we don't actually go and do that ourselves as part of the research team. We hope that it will inform others to build on what we have found, we hope to provide some guiding ideas and concepts and some possible ways to translate them into action, but we don't actually carry out those actions of social change, but a participatory action research project would.

J

Jasmine 24:16

So, as Rebecca was saying, when she spoke about "Nothing about us without us," and doing research with instead of about, I think what is important to talk about is the ways that power is concentrated and operates within academia. And, you know, to actually consider the ways that

we can challenge existing power structures so that more voices are included within academic and research frameworks. There's often an attempt to be inclusive that doesn't actually challenge those power structures. And I think that's when, unfortunately, it can be more of a tokenistic approach to, to research as opposed to one that's really inclusive in the way that we would want it to be.

J Jen 25:08

So, I think I'll be repeating a lot of what Rebecca, Zoe, and Jasmine already said. But I've been involved in many different research projects that use approaches that are very similar to our research. But I think the biggest difference is the active and meaningful involvement of individuals with lived experience of disability in all phases of the research, so we don't just get their input when we have the findings ready but in all stages of the research, including thinking about our recruitment approach, or our method of collecting information from participants. And as Rebecca mentioned earlier, we make sure that the goals of the project align with what is important to them and other individuals with lived experience.

Z Zoe 25:54

I think what makes our project different and unique is that they want us to provide feedback on what will work, what won't work. They want to hear stories, like, from what services we see used for helping, helping. For example, like when we did the public forum, it felt like a whole team, not just like Rebecca, and the researchers. It was Rebecca and all of us. And I also, when we wrote the article, that all of us had input on what we wanted, the the final product of this article that we have written.

Z Zoe 26:55

That experience was, it was like an overall meaningful and impactful experience. But it was also very challenging experience, because we were discussing the stuff that was challenging, but also like, if people are going to read it, then they're going to have like a more meaningful experience that, that we, we can't just let people with disabilities, like participate, or be guinea pigs in research. I don't know if that's too strong of word to use, but we have to let them participate in the boardroom. So I think that's what makes our project unique and different in many ways.

F Francis 27:50

I don't think guinea pigs is too strong of a word to use, Zoe, especially given the history of research on disabled people, on people with intellectual and developmental disabilities, and the ongoing ableism and eugenics present around the world. I think that's an important thing to highlight, so thank you.

F Francis 28:13

Just to build off of my last question to you all, is there anything that stands out to you about the

just to build on or my last question to you all, is there anything that stands out to you about the P2B project, specifically, that's changed the way you think about research?

R

Rebecca 28:27

I think first of all, this research has enhanced my skills related to inclusive research and also deepened my appreciation for the value of using an inclusive research approach. The value of inclusive research really hit home for me in some particular ways. And I'll just give some examples. I think this is something that was raised before, I believe by Jen. During the time when the people on the team who were working intensively with the research and analysis in a way that followed a grounded theory, we would bring what was coming out of the emerging ideas or the emerging themes or categories that were coming out, we would bring those to research team meetings and present them along with some de-identified quotes, so that everyone on the research team could see what was coming out, according to our perspective, question it, ask why certain things were missing or say, "Well, why didn't you pursue this idea in depth a bit more in the analysis," or "Why isn't this idea expressed?" And during those times, some really, really insightful questions came out, particularly from our project consultants, the young adults on the team, Zoe included. As Jen was pointing out, these questions I think made me and others stop and think about how we were looking at these findings because sometimes, questions that were asked, or the insights that were expressed by project consultants, for example, were, were things that, well, I certainly wouldn't have thought of. I didn't see things in that light and it's probably because I don't have the disability.

R

Rebecca 30:17

The second thing I would say, I would say is that most recently, we have been doing some knowledge translation activities in order to produce what are sometimes called products or deliverables. So for example, the research team are working on producing some infographics to convey in plain language and images, what's involved in inclusive research, what is inclusive research, and also some ideas around belonging. What is belonging? How can we think about belonging? Those are topics for the development of our infographics? And also, we have been doing developing some presentations and have some publications and posts in progress. And I guess it's really impressed me how people from all different backgrounds, playing all different roles have come together to produce some of these products, if you like, in a very interesting, creative way. So for example, with the infographics, I know Zoe and Francis, you, and Jen, you're working on some of the infographics, and just the creative way that ideas were brought out, like, in images, it really impressed me! I felt so great, and I thought "Our team did this!" People with different roles on the team worked together to produce this thing that never existed before. And it contains really clearly what our research is about and some important principles that are underlying our research. It, it just was such a great feeling to see that.

J

Jasmine 31:54

On one interview, I was the videographer for a participant who had been formerly incarcerated. And that really led me to think more critically about how police and prisons operate in relation to disability and the disability community. This was also after the 2020 protests as well, that experience really came back and made me think more about the, you know, criminal justice

system and police and prisons, in terms of how people who we've interviewed and people who have intellectual disability more broadly interact with the prison system, and how it affects them specifically. So that was one thing that really stood out for me on the project.

J Jen 32:44

I was thinking while Rebecca was talking about us creating something really amazing together as a team, I think what really stands out for me is the warm and safe atmosphere when we talk about our project and the respect for everyone's experiences and knowledge and abilities. So there's a lot of validation and acknowledgement of team members contributions and opportunities for everyone to get more involved in different phases of the project apart from team meetings, depending on people's interests. So, for example, there are team members who are interested in designing infographics while there are those who prefer to be involved in speaking or writing activities. I think the active engagement has really changed the way I thought about research because it shows that what we have is a partnership and not just a brief collaboration.

Z Zoe 33:35

So I guess what stands out for me the most about participating in P2B was definitely, like, the infographics. When I thought of the fish - I came up with the fish idea. The reasoning behind that was because when fish swim, they swim in a group, so like a school of fish. So I thought, fish, like a group of fish - maybe they, they have a sense of belonging or something along the lines of that. So I thought, oh fish, maybe we could do that and like people with, with our team, and it has been warmly received so far. So. And yeah, I, I would agree with Jen in the sense that like our team atmosphere is very warm and inviting. And I know in the past we've had like celebrations and Christmas parties and like pizza sometimes and that type of thing. So that's also been really lovely as well.

F Francis 34:51

So this - I'll end off with a final question for you all: What was the most enjoyable part of the project for you?

R Rebecca 35:02

While again, for me, there were so many enjoyable parts. And I know they are going to be more enjoyable parts as we continue with the project, but I'll just try to give some examples, I think is kind of the best I can do in the time that we have. Well, obviously, I really enjoy team meetings for all the reasons that I have been mentioning, and everyone else on the podcast has been mentioning, that's something that I really look forward to. I can't wait to hear what people have to say at those meetings. And I love connecting. I guess some of the other things that I have enjoyed is experiencing the talents and skills and innovation and creativity of the team members that, in ways, that I didn't know about. So every phase of the project we go through, whether it's you know, data collection, and analysis or knowledge, translation. Whatever it is, I'm always so impressed with all of the skills people have. It's like, "Oh, you never told us you

could draw! Oh, look at that infographic you created, you know, I didn't know you could use those graphics programs, that is really beautiful work." These are things that allow me insights, more insights into people that I already thought I knew pretty well. So it's kind of exciting to discover those things. And it's just very rewarding to see people shine when they can use their true skills and abilities together to make something that is just fantastic.

J Jasmine 36:35

I am an Occupational Therapist, but I would say my passion, if I could choose, is research. My role is to support individual changes that can take place alongside and working with the youth that I support in my role as a school OT, that's really important to me that I do that work. But I also with this project feel like I'm making a lasting structural and systemic impact that goes to the community level. And honestly, I consider the Voices of Youths and Pathways to Belonging to be, really, what I think is the most important and impactful work that I've done in my career. So I think it's just very important that I continue to be a part of this research.

J Jen 37:29

Okay, my favorite is a crowd favorite. My favorite part is when we create something together, so as Rebecca mentioned, the time when we did the infographics, and Zoe mentioned this earlier too, but there's just, just so many talented people on our team. And it's so satisfying seeing what we come up with together. And whenever we were creating that infographic, I remember, as a researcher, I came to the meeting thinking, you know, I have all these simple ideas where we can probably do this template, you have this text here, simple colors. And then, and then Zoe says "Let's make a fish infographic!" And we talked about how fish belonging looks like underwater, and the actual infographic turned out to be way more amazing than anything I could have created on my own. That was definitely one of my favorite moments with the team and with the project!

Z Zoe 38:28

The most enjoyable part of the project, I guess, is still being part of the of this project. It has become very important in my life. And I guess like, meeting the new people and, but also seeing old faces has also been enjoyable. I think one of the most enjoyable bits for me was when we went to the, went to the Old Spaghetti Factory because we've done the, like, we've completed the Voices of Youths. And I had this idea in my head that we could go buy flowers for Denise, who is our old project coordinator, and Shauna and Rebecca, so we bought - there used to be this flower store at the St. Lawrence Market - I think it's closed now. So, we bought them flowers and we gave them to, we gave them to them at like our dinner, and that was a very enjoyable because like I planned that and then like executed that.

F Francis 39:52

Thank you for listening to another episode of the rehabINK podcast. You can find the Pathways to Belonging website, the article "Working to make research inclusive: perspectives on being members of the Voices of Youths Project," and a film titled "Belonging Matters," which is a film

created by the Voices of Youths team, under "Useful Links" in the podcast description.



Francis 40:14

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