

Podcast Transcript with Dr. Heather Church and Dr. Jacqueline McGinley

Matthew Wappett

Welcome to the ***Developmental Disabilities Network Journal Author Insights Podcast***. This is a new venture for the *Developmental Disabilities Network Journal*, and we are excited to share our first episode with you today. I am Dr. Matthew Wappett, the *DDNJ* Editor in Chief and the Executive Director of the Utah State University Institute for Disability Research, Policy and Practice—Utah’s University Center for Excellence in Developmental Disabilities. It is my privilege to host this podcast. As I mentioned earlier, the podcast is called ***DDNJ Author Insights***, and the podcast will include monthly interviews with authors from the latest issue of the journal. Each episode will be structured as a conversation with the authors and will provide a more informal opportunity to explore the author’s article in the journal. But it will also include some fun, behind-the-scenes insights on the author’s process of designing, implementing, analyzing, and writing up their work. We also want to use the podcast as an opportunity to acknowledge that authors are more than just a name on the page. And we want to help you get to know the people behind the publication. We want to help you gain a better understanding of the many diverse voices who are working in the field today. And we want to provide some insights into what motivates authors, where they get their ideas from, and why they do what they do. I think most importantly, however, we launched this podcast to increase the accessibility of the content in the *Developmental Disabilities Network Journal*. The launch of this podcast is part of our ongoing commitment to increasing the accessibility of the journal for a wider readership. Not everyone has time to sit down and read an entire article these days, and more and more people are choosing to get their information through podcasts, audio books, and other options. The launch of this podcast means that you can access *DDNJ*’s content while you are on the go—and you can share it more readily across social media and other online platforms. We recognize that it is important to present our information through a wide range of media and formats. We hope that this podcast will provide another alternative to access the information within the journal. So, it’s incredibly exciting for me to visit with the authors who are featured in the journal. I learned so much from these conversations and I hope that you will too.

The first episode of our podcast today is an important conversation with Dr. Heather Church and Dr. Jacqueline McGinley, two of the authors on an article entitled, “*Advanced Care Planning Within Individualized Care Plans: A Component of Emergency Preparedness*.” This article can be found in the most recent issue of *DDNJ*, Volume 2 Issue 1. Dr. Heather Church is faculty in the Health Sciences at Brock University in Ontario, Canada. Heather has a PhD in Health and Rehabilitation Sciences and specializes in health policy, health equity, developmental disabilities, and mental health. She has enjoyed working with people who have developmental disabilities for 20 years, and over her career she has been driven by a commitment to removing barriers to inclusion and full participation. Dr. Jackie McGinley is a licensed social worker and Assistant Professor in the Department of Social Work at Binghamton University, part of the State University

of New York system. Dr. McGinley earned her MSW from Rutgers University's School of Social Work and a PhD from the University at Buffalo School of Social Work. She also completed a year-long fellowship with the LEND program at the University of Rochester—receiving advanced research and clinical training there. Her mission as a social work scholar is to lead translational research that improves care for people with disabilities as they age, experience serious illness, and reach life's end. We felt that this article was a perfect representation of the type of work that we like to highlight in the *Developmental Disabilities Network Journal*. This is research with immediate, real-world applications and Dr. Church and Dr. McGinley share some poignant stories and timely insights that really shift the way that we think about transition planning for older adults with disabilities. So, without further ado, here's my interview with Doctors Church and McGinley.

Thanks for joining us today, Heather and Jackie. We're excited to talk about your work in this latest issue of the *Developmental Disabilities Network Journal*. Your article in this latest edition is called "Advanced Care Planning Within Individualized Care Plans: A Component of Emergency Preparedness." I would like to start with you, Heather. You are the lead author on this. I would like to just get your perspective, give us a little bit about your background, and the path that brought you to this project.

Heather Church

Certainly. So, for about the last 20 years, I have been working with people who have developmental disorders here in Ontario, Canada. And that's actually how I came to meet Jackie and the rest of our research team—at the International Association for Scientific Study and Intellectual Developmental Disabilities Conference. And we got to talking and sharing ideas. And then Jackie came up with this wonderful research that we did. And but from that, from my own experience, was that working in the field of developmental disabilities, we really, I noticed that we don't do a good job of planning for the future. So, for young children, we don't think about transitions until it's happening. And then it transitions into adulthood, and then just transitions across the lifespan in general, so that people end up in positions where it's a sudden scramble. But we in the field know that these are things that are coming up and can be planned for. And we also know that when we plan for things, people have an easier time moving across into the next stages of their lives. So, for me, that's really where this hit home. My own PhD research was looking at community-based care and health equity impacts thereof, on people who have developmental disabilities and their families. And that the themes that kept coming up were the long waits for services and never really knowing what to expect and what was available. And then we found ourselves in the pandemic and lockdowns and services being disappeared. And I started wondering how all those participants were coping within that context. And so that's where I decided that was really important to me to look at how we can actually use what's happened now to prepare for the future.

Matthew Wappett

Perfect. And what about you, Jackie? You're working across the border, I guess. You're in New

York, right? And so, it's interesting—you've got this cross-cultural collaboration going on. What about your background and what path brought you to this this project as well?

Jacqueline McGinley

Yeah, so one of the best things about this project has been that it has been a transdisciplinary project and it's also been cut across—I think we're up to four or five states in two countries now. But before we began this work, I, similar to Heather, spent about 20 years in the field of disability. I've done everything from volunteer to consult, to serve as a behaviorist and administrator. So, I've worn a lot of hats in the field. Most recently, I went back to school and earned a PhD. And my work was in specifically end-of-life care for people with intellectual and developmental disabilities. And part of that emerged from my time as a social worker. So that's my discipline—I'm a social worker by training. And what I constantly saw is what Heather was mentioning when she was talking about her work, which was, particularly for the older adults that I was working with, we did not do a very good job planning for transitions. It was, "Oh no, a person is in crisis, they can no longer go to day program," rather than a few years out having conversations about retirement or long-term planning. So, we were always responding to crises instead of thinking ahead and planning thoughtfully for individuals for what we knew was going to happen, which was that they were going to age, that they likely would become seriously ill, and that they, like all of us, would reach the end of their lives. So that's kind of how we ended up with this project and this work that Heather so beautifully wrote up for the journal.

Matthew Wappett

Yeah, I know it's a, we talk a lot about transition within the field, but we're usually talking about right transition from early childhood into school, or transition from school into post-secondary or work—we're rarely talking about transition on the far end of life. So that's where I think this is really important work. So, you bring this up in the article, and you've probably done other work on this, but why don't people with disabilities have advanced care plans? I guess we can start with you, Jackie, this time, and then we'll go to you, Heather.

Jacqueline McGinley

Sure, so I want to contextualize this a little bit. Most people don't have advanced care plans. In fact, the data suggests that, you know, somewhere between 25 to 30% of people have an advanced care plan. Those numbers do go up as people get older—they go up for certain groups of people. But most people don't plan for the inevitable. And I think part of the reason we don't talk about this, and we don't plan for it, is it's really scary. It's scary to think about getting sick, it's scary to think about dying, and especially just scary to think about that for other people in our lives. So, to think about and initiate those conversations with our loved ones...I'll let Heather talk a little bit about this more, because she had a lot of work around caregivers. But why that's super hard and scary I think for caregivers to have those conversations around themselves and around their children with disabilities just adds another layer to it that makes, I think, people even more unlikely to have those conversations.

Matthew Wappett

So, tell us a little bit about your perspective on the Center.

Heather Church

I agree completely. I think that's absolutely right. And with our population, we do see that caregivers are also. They don't know what's available. And you know, it's very scary. And that's one of the things that frequently come out when you're talking about transition to adulthood, or as people are getting older, and noticing that the caregivers themselves are losing capacity. They start reflecting on what's going to happen when I'm gone. But it's a scary thing and the options...and by that time too, there is a lack of confidence in the system, because of all the gaps that they've gone through and all the fighting that they've had to do across their loved one's lifespan in order to get the services that are needed and in place when they are needed. So, I think that's another layer that really is challenging for our population. And I think also, there's also that piece where we do see that people are so caught up in advocating for meeting current needs. But even waiting and crossing that bridge when we get to it for the long term feels more manageable.

Matthew Wappett

Yeah, so we don't want to give away everything here. We want people to go and download and read the article. But give us a quick summary of the article in about two minutes—kind of summarize your main argument here.

Heather Church

Okay, so we looked at code, the impacts of the lockdowns, and COVID-19 itself, and how that's influenced access to services as sort of a context for understanding how advanced care planning can be built into an individual service plan. And one of the key things for me is that whole piece of rehearsal allows for more effective transitions. And so I think, for me, my key point is simply that, if we do it ahead of time that we can actually give the person who is going to be living through these transitions an opportunity to practice it so that it's not unfamiliar in a time of crisis.

Matthew Wappett

Right. I think that's something we might all benefit from. So, through this process, and through this work, it sounds like you've both been involved in various roles and have kind of intersected with this in various ways throughout your careers. Jackie, could you share with us a memorable story or event that's occurred that maybe motivated you to do some of this work?

Jacqueline McGinley

Yeah, definitely. So, I don't remember the year it was, but I remember I had a lot less gray hairs.

I know the audience can't see the number of gray hairs I have now, but there are many. But I was a social worker for a disability organization in New Jersey. And in my role, I was responsible for helping to write and plan for services for individuals. So, I was on the front lines of writing the Person-Centered Plans that we talked about in this article. And I had a client, she was in her mid-70s, that I was supporting. And I had gotten worried talking with her and the staff that supported her, talking with some people in her life that cared about her, and from interacting and observing her. She used some sign language to communicate, she also had a lot of individual ways that she communicated. And what was becoming loud and clear the year I was helping to write her Person-Centered Plan was, she was ready to retire—she was in her 70s and she no longer wanted to go to work. And I understood that—everyone understood that. And I remember sitting down at the meeting that we held, most individuals with disabilities have annual or semi-annual meetings where they bring together their circle of support, they talk about what's been going on, they plan for the future, ideally. So, we were having that meeting, and I broached the subject of retirement. And the room went silent. It was as though the idea had never occurred to anyone before—that someone may want to retire! And it was the bizarrest thing to me. I still can like, move myself and be in that room again. And I thought, there's got to be a better way. We should be able to plan for and have the supports in place to allow people to live out their later years how they so choose—and we just didn't. And so that little gem of an idea has been kind of in the back of my mind for a really long time. And I feel like a lot of the work that we did for this project is in service to that woman. She's since passed away. Actually, I write about her life in another study that I did. But a lot of this I think about her, and I think about wanting to give people the opportunity to retire, wanting to give people the opportunity to have their cat on their bed while they're sick, wanting to give people the opportunity to access hospice care. And it starts with conversations about those wishes. And we don't have them enough. And that's really where I feel like this work comes from.

Matthew Wappett

That's such, that's such an incredible story. Because I think, yeah, we avoid these conversations. The expectation, right, is you're going to work tell you can't work anymore. We're not really playful. And when you can't work anymore, then we'll deal with it when it kind of comes up. But yeah, the rest, you know, again, when we talk about retirement, particularly, right, a typically developing population, you have retirement planning, you're having these conversations—at least a lot of people are—not everyone. But you're right, this is a conversation that is not had among the population of people with intellectual and developmental disabilities. So, Heather, what about you? What's an interesting, memorable experience that's occurred as you've worked on this?

Heather Church

So, one thing that I do have, I have a psychotherapy practice. And because I specialize with people with developmental disabilities, I do see a lot of people coming in who have developmental disabilities or supporting them. And I had one client who had Down syndrome. And he was middle aged. And he had moved in with his sister following the deaths (in short order) of both parents.

And they had come to a place where they'd gotten the logistics sorted out, but we're butting heads now. And she was referred to me because she said, you know, we're having some really big behavioral problems, and we can't figure out what's going on, and what have you. We've got everything, we've got all the visuals up, we have a routine set. So, we thought everything would be predictable at this point. So, then he came into my office. And one day in particular, he was just really agitated. And so, we just sat there for a moment. And all of a sudden, he said to me, "Nobody ever told me they were going to die." And he just, he was so fixated on that and just started talking. "Nobody ever told me they were going to die." And then he described what happened. So, one minute I was in my house, the next minute mom fell, ambulance came, and then I had to go to my sister's, and I've never been back. And so that right there was an "aha" moment. This was...Jackie had already approached us with the work that we're doing together. And, wow, that really hit home that it is that those emergencies and those crises that just pop up. And there's that lack of accounting for the emotional experience that the person's having. Whereas we all take it for granted that we get it—we know what's going to happen. But if they haven't been included in the conversation, how can we ensure that the people most in need of understanding—the people are most impacted by—are going to know.

Matthew Wappett

That's an incredibly poignant story. I mean, what I mean, that quote, I think is actually going to stick with me—"Nobody ever told me they were going to die." That's just that, how unfortunate that we haven't created a system where we have those conversations. So, I'm going to spring a question on you that wasn't in my original list, but it's come up as we're talking here. So, if you don't want to go for it, just say I/we can't answer that. But the question is, "What supports are out there for people who are interested in learning more about advanced care planning and having some of these retirement, end-of-life sort of transition conversations?" Are there supports—are there curricula or people or programs that people can go to?

Jacqueline McGinley

Yeah, so I'll jump in here. There absolutely are. And this is kind of the interesting thing about this is that there are a number of resources that are available to people. Oftentimes, it's just initiating the conversation and introducing those resources to individuals. I think that happens a lot in any sort of services that we offer. Much exists, but sometimes there's a gap between that resource and it being in the hands of families or them being supported in utilizing it or the hands of individuals. So, for example, the ARC has a wonderful portal around future planning, where they have a really comprehensive tool that people can access to develop their plans. There's a lot of folks in the United Kingdom who are doing FANTASTIC work around this. And we can share this for the show notes, if that's at all helpful for individuals who are doing a lot of work in this area and have a lot of tools that are in plain language and easily accessible to individuals. So that you don't need to rely on caregivers or families to use them, they can really be done directly with individuals. So those are just two. In addition to that, there's a lot of tools that have been developed for anyone to use. For example, "Five Wishes" is a very basic advanced care-planning tool that is available. And a lot of these tools during COVID...actually, these have previously been

behind paywalls, but during COVID, many of them became publicly available. And then the last thing I'll just add to that, too, is there is a dimension of this that deals with local laws and regulations. And so, it does behoove people that are getting into things like medical orders, such as a "do not resuscitate order," or like a health care proxy, are some of the things we have here in New York State and other places. If you're getting into some of those tools, you do want to look towards your local Department of Health or even a local provider who can direct you in some of those tools. Because some states and some nations require very specific tools, including very specific tools for people with developmental disabilities, especially when we get into healthcare decision making in specific moments. So, we do make a distinction between "Advanced Care Planning" and "Advanced Directive." So "Advanced Care Planning" are the conversations we have with others about what we want if we no longer are able to speak for ourselves. Whereas "Advanced Directives" are those often legally binding documents that we use to articulate our wishes and who we want to speak for us or make decisions for us if we are unable to. So, anyone at any time can engage in Advanced Care Planning. But when it comes to the Advanced Directives, you just want to make sure to check with your local provider or a local agency that does this work to make sure that you have the right documents in hand in the moments when you might need them.

Matthew Wappett

Yeah, absolutely. And I would guess that, you know, as those tools vary across localities, states, they probably vary across international lines, too. So, are those tools that you mentioned, Jackie, also applicable in Canada? And are there tools that are specific to Canada that listeners should maybe know about, Heather?

Heather Church

Well, again, Jackie's absolutely right. We go province by province for long-term care decisions. But when we were looking actually...we tried to replicate the study in Canada. When we were looking at it again, there's not that same consistency. And it does very much depend on who the service provider is and whether or not their eye has been focused on that as an issue. But again, we also do look to see, you know, what other countries have done. And so, you going back and forth across those different tools that are available in different countries has been helpful.

Matthew Wappett

Yeah, that's great. So what? What is the take-home message from your article here? I think we can guess based upon this conversation, but I'd like to hear from you. What, you know, if you had to summarize it in one sentence, what would you want the listeners to take home with them?

Jacqueline McGinley

Um, we know what's going to happen. So why not plan for it...make life easy.

Matthew Wappett

Fair enough. That's come through very loud and clear here. So, kind of shifting, one of the things we like to do is get to know some of the researchers who are publishing in the *Developmental Disabilities Network Journal*. So, I'm just curious, you know, kind of going back to our initial question about your background and stuff. What is it, for each of you, that motivates you to do this work? So why don't we start with you, Heather, and then we'll go to Jackie,

Heather Church

People. I have met so many fascinating and interesting people. And actually, I wanted to share a positive story, too. So, many moons ago, when I first got into the field, I worked with a little boy who, he came to us at our center, and he was nonverbal, and very frustrated, and a very behavioral little boy. But he became, very quickly learned, really well and became very communicative. And, recently, on social media, there was a post by his mother celebrating that he had achieved his lifelong goal and voted in his first election. And it was just so wonderful, because he was very intelligent, he still is, but he very intelligent little boy, and very aware of his surroundings, and just needed to be taught how to organize his thoughts so that he could express them in a way that other people would understand. So, it was just so exciting to see that he was able to go and vote and make an informed choice.

Matthew Wappett

Incredible. That's yeah, what a great...what a great story. What about you, Jackie, what motivates you?

Jacqueline McGinley

So, when I, when I was deciding to go back to school, I went to my mentor from practice. And I said, I'm thinking about going back to school, would you be willing to write a letter of support for my application? And she said, and she looked me like dead in the eye and said, "Yes, but you better not forget about us." And that was the promise I had to make; it was sort of the deal I had to make to get that letter of support. And so, when I think about the work that I do, at least the work that I feel like, like this work that I feel particularly connected and proud of, it's because of in service to those clients who welcomed me into their lives and let me sit at their bed as they died. And the staff who, you know, we cried together when we lost individuals...it's in service to them this work. And so that's, that's who I think of when you're sitting at a computer at 4 a.m. typing up papers is those folks and the lessons they taught me. Yeah.

Matthew Wappett

Thank you, thank you for sharing that. It's always just incredibly inspiring to hear, you know, that human connection and just how that human connection can be so motivated and important to what we do. And not just so...the last question that we want to ask...one of the big focuses of this

journal is trying to make information, and particularly research, more accessible and inclusive. “What is one thing you’ve been doing to make your work more inclusive and accessible?” And let’s start with you, Jackie, this time.

Jacqueline McGinley

Yeah, so this is something I think about a lot. And I also think about it as a lifelong process. And I’m not where I hope to eventually be, but I feel like I’m moving in the right direction. And I think where I am right now is relying a great deal on community partnerships to help me form the research questions I asked. For example, this past year, while I was like everyone else coping with the pandemic, I had a lot of one-on-one interactions with students just through outreach. I’m a professor at the University. And what became very clear is that there are some elements of the pandemic that were working really well for students with disabilities, and there were other parts that were definitely challenging. And so, I started a conversation with my students around that topic—what’s working and what’s not. And that actually became the basis for a research study that I undertook with some colleagues last year. So, I think for me, it’s really, when I just even am starting with an idea, making sure it’s grounded in the things that the people I seek to serve or wanting to know more about, or wanting other people to know about.

Matthew Wappett

That’s incredible, that sort of participatory, community-based research approach is just becoming so important, I think, to the field of intellectual and developmental disabilities. So Heather, what about you? What are you doing to make your work more inclusive and accessible?

Heather Church 30:52

Well, it’s interesting, because as Jackie was talking, I was thinking about here in Canada, a lot of our indigenous advocacy groups rely on the expression, “Nothing about us without us.” And that’s that whole idea of “don’t go making policies and programs without consulting with us first.” And I think that that can apply to anybody. You know, if something is going to impact on your life, you kind of want to have some input on it. And I think that’s really important—getting those voices heard and informing what we’re doing, instead of basing it all on what we think we know. And then also too, I think there also reflects a real value for qualitative and quantitative research. And I think, as we move increasingly to a digitized society, there is a tendency to rely on algorithms and what have you. And I think it is important to also keep in mind that we have to understand the reasons behind those numbers and making sure that we’re not just making assumptions about people’s lives and what they want and what their priorities are.

Matthew Wappett

No, I think you’re exactly right. I actually heard somebody say the other week that algorithms aren’t individualized. And I think that’s a good thing to keep in mind. There is a big push towards big data these days. And, unfortunately, yeah, sometimes the individual can get lost within that,

within that push. So, thank you both. for your time today. This has been just a delightful conversation. I feel that this work is incredibly important. And we hope that the listeners will certainly take something from this and hopefully reach out to you. We'll make sure that we share some of the resources that you brought up on the website and on the show notes. And yeah, just thank you, thank you, thank you so much for doing this.

Heather Church 32:46

Thank you so much for taking the interest.

Matthew Wappett

Yeah, you bet. So that's going to wrap up our inaugural episode of the ***Developmental Disabilities Network Journal Author Insights Podcast***. I hope that you enjoyed that interview with Dr. Church and Dr. McGinley. It was certainly a pleasure for me to visit with them and I learned a lot just through our correspondence and our conversation...things that, you know, in the past have not been first and foremost in my mind, and certainly not within the planning and other work that we do. So hopefully, their insights on advanced care planning and how we integrate that into the lives of adults with disabilities who are aging and support families through this process is going to be helpful to you and for your work moving into the future. As always, thank you for listening, please make sure you subscribe to the podcast on your favorite podcast app. As I said, we'll be putting out new episodes monthly so this will be regularly updated. So, whether you listen on Apple Podcast, Spotify, Stitcher, Overcast, or something else, please subscribe so that you don't miss an episode. Also, please make sure that you leave us a rating and a review. Your feedback helps us make the podcast better and will help more people find us. And then finally, please, because this is new, share this podcast with your friends, your family, your colleagues, and others who might be interested in these conversations that we're going to be having. Stay tuned for our next episode. It'll be out in early December and until then keep smiling—even a passing smile, a friendly nod, or a knowing wave can brighten someone's day. So, thanks, everybody. Have a great one. We'll see you next time.