

New journals seek to fill neurodiversity gap

The two journals, although differing in initial support, both realized the need for a publication focused exclusively on the neurodiverse experience.

8 March 2023 | by Brady Huggett

Interview with Marie-Eve Lefebvre, *Journal of Neurodiversity*

This transcript has been lightly edited for clarity.

Brady Huggett: I'm Brady Huggett, the enterprise editor at *Spectrum*. This is an interview with an editor of a new journal that will operate in the autism research space. It's called the *Journal of Neurodiversity*, and the editor's name is Marie-Eve Lefebvre. This interview was conducted December 19, 2022, as part of an article titled "New journals seek to fill neurodiversity gap." OK, off we go.

So I think the first thing that we want to ask, of course, is how this journal came to be.

Marie-Eve Lefebvre: Actually, I started my Ph.D. in 2019. And I was always interested in autism in adulthood. I really enjoy, like, learning about that. I do have an autistic part of myself. So I was really curious about what we know about that. I came across little — just limited amounts of literature about that. And that was a good start for my Ph.D. because I felt like I could make a difference. But then, I just feel like I couldn't do much by myself. I felt like I had to have a platform, to have a place to encourage other people to publish on that topic. So that was something in the back of my mind. But then I didn't really plan on founding a journal before I got a professor job, or something more stable. But then I got to chat with my friend Justine. And she asked me what was in the way, like what needed to be done to make that project happen. And I wasn't really sure. I wanted to be stable, but then there is a momentum right now. We talk about neurodiversity a lot — mostly on social media — but then in the research literature, it's quite limited. Like I said, it's the same as in autism in adulthood. It feels like whether it's autism, giftedness or learning disability, when you go into adulthood it's really limited. So I feel like we could go broader, and we could do something bigger than just me and my subject.

BH: I'm sorry, you're saying the research on autistic adults was limited? That's what you were struggling to find?

ML: Yeah, yeah, exactly. Especially — we're based in Montreal, Quebec. Here, we do have the research in French; we do have the research in English. But then in French it's really limited. We do have some things in English, but then working here mostly in French, it feels really, really limited.

BH: Mm-hmm.

ML: So I wanted to do something that would encourage that movement. And then I talked with Justine, and she was really encouraging. Like, we could do something, we could do a journal. It doesn't have to be in a couple of years. So we got to, we got to work, actually. We had this discussion last fall. And slowly we started working on the website; we started working with the University of Montreal to make that thing happen. For — how can I say? — for financial support and all of that. So we really got to work.

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BH: Working on the website for the journal itself.

ML: Yeah, the website. And figuring out all the details, like how we would evaluate all the manuscripts, what type of manuscript we will accept. Also, like how broad it is, because we are in educational science, but then we also feel like neurodiversity is part of education, sociology, psychology, so it's really complex. So we are really in the humanities, the way we feel about it, but we're really accepting all types of perspectives.

BH: So, two things: You grew up in Canada?

ML: Yeah. I grew up in Canada. In Montreal, Quebec, yeah.

BH: And you said you have an autistic parent?

ML: Yeah, I do.

BH: So that's, that's your initial interest in this field, then?

ML: Yeah. Actually, when I was younger, he got his diagnosis. But then — it was difficult because it was first bipolar, and then after it was just depression. And for me as a child, it was quite difficult because I just didn't understand what was going on. And he, unfortunately he passed away when I was in college. And it just feels like there was a lot of questions unanswered. So for me, my primary motivation as a researcher is to understand what happened, like, for me, as a part of the grief with everything. But also like, I got to work with other autistic adults. And I felt like what my dad lived was not something isolated. It was something, it was a reality that was shared by other autistic people. So that was really the main point.

BH: Right. So it was — you kind of wanted to satisfy your own curiosity about your father, who was, you know, he was no longer around, and you couldn't ask him questions.

ML: Exactly.

BH: And then also you realized that the field itself, there wasn't — well, I think that's my question. Did you feel like there was not one receptacle for this kind of research?

ML: Yeah, exactly. It feels like the more I educate myself about autism, the more I feel there was a different paradigm. And neurodiversity was not something that was very — let's say, present — in literature. It feels like it's really emerged since maybe 2010.

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BH: Yeah.

ML: So it's really recent. When I came across that movement, I just felt, like, such a fresh breeze of air. It just feels, like, so new and so refreshing. And I was like, we need to do more of that. We need to have a movement, like, something in the science. But then not only scientific research, but then a place where we can really exchange about that with practitioners, with autistic people, or neurodivergent people in this case, and you really have a space for collaborating.

BH: Yeah. So there's a bunch of questions I want to ask. Who is the publisher?

ML: So far, it's the first year of the journal. So we're still figuring out, to be honest, how we're gonna do the publishing process. We are in contact with the University of Montreal to have the funding and everything. So right now we are in this great state of mind, if I may say, where we are still looking. And we had such a great response that we want to do good. We want to have a good publisher, we want to have something that's solid, especially for the next couple of years, because I feel like there is a lot of positive response from the community. My peers who are also neurodivergent, but also from research, where it feels like it's a new area. It's a new discipline in itself. So for now we're still working on it.

BH: So, you just mentioned this thing. I'm wondering about representation in the journal. I'm assuming, you know, maybe on your board, probably your editor — some of them are going to be neurodiverse. Is that correct?

ML: Yeah, exactly. Actually, the board, right now, we are only four people. And then it's all neurodivergent people or people suspecting to be. So, myself, I'm a neurodivergent researcher. And it feels important to see ourselves in this research. But we're also — because it's a space where we exchange, where we want to do, maybe start some reflection about research on neurodiversity, we want to involve as much people as possible. So that includes researchers, but also practitioner people who work with, in this case, autistic people, but neurodivergent people on a daily basis. But also just normal people who are going to be able to have their point of view to share it with us, and to really see, like, is that really important? Is that disconnected from their reality? So we're really in a space where we're trying to make bridges, if I may say. We're trying to construct a bridge between the different actors of the neurodiversity movement.

BH: So you feel like your audience is who, then?

ML: I feel it's people who are influenced directly or indirectly by neurodiversity. And it's broad. That is true, it is broad. But it also — it feels like it can really start making transparent research and making transparent processes by applying to so many people. It could be someone who has a child that is neurodivergent. It could be a teacher;

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it could be a practitioner. Right now, we're not there. Right now, we're all researchers, who are questioning if they are neurodivergent. So we are more in this perspective, but we would like to have more people that are not in research, so we could have other perspectives. So we could also learn from that, learn from their priorities or learn from their need, and really establish, maybe, this journal based on that collaboration together.

BH: So is it fair to say that anyone who might be looking — let's say the journal is 10 years old at this point? OK.

ML: Yeah.

BH: I'm imagining a future, and anyone who is looking for information on academic studies about neurodiverse life, they might find it in this journal. That might be parents; that might be somebody who suspects they might be neurodiverse. That might be someone who has a diagnosis; it might be researchers; it might be clinicians — all those people should be an audience for this journal, you think?

ML: Yeah, totally. And I really hope, I think, to make this knowledge more accessible. And to make it, if I may say, closer from, like, the real need? From autistic people's needs, from people with ADHD's needs. So, really take into account that, because we know — if you're a little bit aware of the literature on neurodiversity — often we're really interested in the parents, the people around those people. But it's sometimes difficult to reach them, because the methods are not adapted. Or maybe it's hard, or maybe we prefer to go by the practitioner point of view. But it's really trying to remove those walls, really.

BH: And then, can we talk about the kind of content that will be in this journal? I mean, I know that there — it's also very broad, right? I mean, there's going to be a social studies aspect, humanities, but also biomedical research as well. Is that correct?

ML: Yeah. Yeah, it feels like neurodiversity is a very complex subject, like I said, and we cannot really approach it from one perspective only. We have medical studies; we have psychological studies, educational studies, and it's really a place for that. To have a multidisciplinary perspective, and the content that's going to be coming from that. Really, we have three types of manuscripts that we're accepting, other than the broad research discipline. We do have research articles, but we also accept professional articles like you mentioned before, and also a personal testimony. So we are really trying to have a broad perspective and a multidisciplinary perspective.

BH: So personal testimony: things like opinion pieces. Like that?

ML: Yeah, exactly. We were taking — when we were finding ideas for the first call for proposal: What is it to have a late diagnosis? What is it to disclose a diagnosis when you're in your workplace? How is it to manage stress? Or, you know, finding out you have some limits in your daily life? So it's stuff like that, where people can

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really take the space and talk about them, and talk about their experience. And really have that read by other people, by researchers, by practitioners, and really have this exchange.

BH: But again, this journal is focused on adulthood. Right? Neurodiverse adults? Or no?

ML: It was first my idea to do that, but then when I was talking with Justine, we felt like it was going to be too limited.

BH: Yeah.

ML: Because right now, the research is limited. So even though we step outside of research, and we talk about practice, and we talk about personal experience, we don't want to restrict people to that team. So personally, I do have — I'm a specialist in adulthood. But I feel like, for example, Justine, she's more into teenagers, younger children. So we are really more — I don't know — complementary in that aspect. So personally, I'm more into it. But the journal itself is broader than me, and that was the idea behind that.

BH: So I think maybe one of the biggest divides in the neurodiverse community right now is possibly this thought of, you know, things like autism being biomedical or social, right?

ML: Yeah.

BH: And there are people who will stand on either side of that divide. And I'm wondering how you're going to balance that in the pages of your journal?

ML: Yeah, that's a really good question. Because I think right now, from recent research, from talking with other colleagues, it feels like there's two themes: biomedical and social, like you mentioned. But the neurodiversity movement, I think it's not about one team or another. I think it's really about highlighting the positive aspects, highlighting the strengths, being proud of this identity. So whether it's from a biomedical perspective or whether it's from a social perspective, I think it's not incoherent. It's still possible to present both. But I have to agree that from the last couple years, usually it's more of a social model that's going to — let's say — be in the same direction as the neurodiversity movement. But I feel by not excluding the biomedical movement, since a lot of practitioners are still based on that model, we're encouraging to create a bridge between those. And to see that they're not that different, and that the perspective is changing slowly.

BH: I mean, it's possible that you will publish things that some of your audience are not going to like, then. On one or the other.

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ML: Yeah, totally. We're ready for that. It's part of the discussion.

BH: And also, this is open access, correct?

ML: Yeah, exactly. We don't want to have a membership or anything like that, because that will be against what we're trying to do. We're trying to make that accessible for either neurodivergent people, practitioners or researchers. So we really want to have that open access.

BH: And then, what's your publishing schedule going to be?

ML: Actually, we released our first call for proposal this fall. So that was really exciting. And we're working right now for one, one number? I'm sorry; I'm forgetting. One edition? I'm not quite sure if that is the right term.

BH: That's the right term.

ML: OK, so we're looking for one edition per year for now, because we're a small team. We're a team of four people. But we are willing to — I mean, we know we're going to grow; we know we're gonna get attention. So we're going to go probably to two editions per year by next year or in two years. And we're going to see how much people are willing to publish with us, to accept this new project. And really, like I said, we're really flexible, and we're still in the first year. So we don't want to go, let's say, do too much. And to do it badly. We really want to do things slowly and solidly, so that the platform itself has a good recognition; people find it trustworthy; they have trust in it. So we're really trying to aim for that.

BH: How will you gauge your success? I mean, are you thinking about things like impact factor, citations or just readership? Or what is it?

ML: Yep, yep, exactly. We, unfortunately, because of some — let's say, how can I say? — administrative details, the journal has to be two years old before going into the impact factor. So for the first two years, we're going to go with the basic statistic, but we are aiming for impact factor. We're aiming for more than just as a statistic, and really to be comparable to other journals in this field. For example, *Autism* — have you heard? — that has this impact factor, citation index and all of that.

BH: So — again, this might be too far down the line for you to think about — but are you thinking about some sort of business plan where this is able to bring in money somehow and be self-sustaining at some point?

ML: For sure, because of the financial support, the publishing process, cost of money, having also a DOI access — either, like, having access to DOI through our article, or finding online to DOI — we have to have some

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financial support. And we're trying to establish some recurring support in that regard. But we're not going to make money out of it. If I answer the question really simply, that's not the goal. The goal is to have something that is going to give back to the community that we're going to start, and other people are going to contribute to it. And it's not only yourself; it's really like a broader thing to us. So like any researcher, a journal is great when you get into a position or editorial board, but it's not something to make money off. It's really to encourage greater knowledge, for sure.

BH: Yeah, no, I totally agree with that. But the concept — I mean, I think you are paying your editorial board some amount of money, right?

ML: Yeah.

BH: I mean, it does cost something to produce this. So is there some way that you can recoup some of those costs, I think is the main question.

ML: What do you mean by recoup?

BH: Gain back some of the costs?

ML: Yeah. Yeah. Actually, we're not there. Like you anticipate, right now, it's purely volunteering, because we are really driven by this project. But for sure, we would like to have some of the investment returned back. We're not there yet. I think it's more in two or three years, we're gonna see if it's going to be possible. But right now we are, we're aiming for volunteering. But we are aware that it's not going to last forever, because we're all really busy. And we're all very interested in the project, but at some point, it's not going to pay the bill. So we are — let's say it's a process. And we're not there yet, because we decided to be kind of modest about it. But we know in the next couple of years, it's going to be — we're going to be able to find some financial support for ourselves as well as the journal itself.

BH: So I have one final question. When can we expect the first volume, the first edition?

ML: I would say next summer, but the call for proposals, the first one, is ending at the end of [December 2022]. So the 31 of December, we're going to review the papers, whether it's scientific or personal or professional, we're going to review it in the next month. And after, we're going to be in touch with the other colleagues for peer review. And that is going to be for only scientific papers; other types, such as professional and personal, are going to be reviewed by the editorial board. So that's going to take some time for sure. But we're aiming for either spring or early summer.

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BH: So spring, early summer, next year, the first edition.

ML: Exactly.

BH: But you touched on something that I should have mentioned before. So this is peer reviewed, the scientific papers that come in will be peer reviewed, and the things that are more about opinion pieces or testimony of life, that is going to be reviewed by the editors.

ML: Exactly, yeah, the scientific manuscripts are going to proceed the same way as any other journal; that's not going to change. But because we are into, like, we are in a neurodiversity perspective, we're going to reach colleagues that are specialized into this area. And this is going to be double blind as well. So it's the same as any other journal.

BH: Yep. That's it. Thanks for taking the time to talk to us about this.

ML: Thanks to you. Thank you for the opportunity, and I'm happy to be able to share that with other people.

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