



Re•Storying Autism:

An interview with Patty Douglas and Carla Rice

Interviewed by David Denborough



Patty Douglas is Associate Professor of Disability Studies in Education in the Faculty of Education at Brandon University in Manitoba, Canada. Her work in disability studies concentrates on critical and creative approaches to autism and care as supported by feminist, queer, decolonial, critical post-humanist, cultural studies and other critical approaches that dislodge the (humanist) human in educational research and practice. Patty leads the Re•Storying Autism in Education project, a SSHRC-funded international, multimedia storytelling project that challenges deficit

stereotypes of difference to transform policy and practice. More information can be found at: [@ReStorying](http://www.restoryingautism.ca)

Carla Rice is Professor and Canada Research Chair in the College of Social and Applied Human Sciences at the University of Guelph, specialising in neo-materialist theory, embodiment, fat and disability studies, and arts-based and creative methodologies. She founded Re•Vision: The Centre for Art and Social Justice as an arts-informed research centre with a mandate to foster social wellbeing, equity and justice. Currently, Carla is principal investigator and co-director of Bodies in Translation: Activist Art, Technology and Access to Life, a funded partnership grant that seeks to cultivate disabled, d/Deaf, fat, Mad and aging arts using a decolonising lens through engaging with many community and institutional partners. She has received awards for research and mentorship, and has written on embodied difference, non-normative cultures, and accessibility and inclusion. More information about the Re•Vision Centre can be found at: <https://projectrevision.ca/> and about Bodies in Translation at: <https://bodiesintranslation.ca/>. Carla can be reached by email at: carlar@uoguelph.ca.



Abstract

The Re•Storying Autism project is a Canadian–British collaboration that seeks to interrupt dominant and limiting narratives of autism through an alternative storytelling process. Short films made by people who identify as autistic or who have attracted a label of autism tell preferred stories that shift understandings, expand representations and create space for practices of difference. Carla Rice and Patty Douglas, two of the project leaders, caught up with David Denborough to reflect on the principles and practices embraced by the Re•Storying Autism project, and to consider the project’s potential for contributing to a framework that may be useful to narrative practitioners.

Key words: *autism; narrative; film; neurodiversity; disability studies; storytelling*

David: I'm interested to hear more about the Re•Storying Autism project¹ that you've written about and that's been taking place in Canada, and now northern England. It seems very significant.

Carla: Under the leadership of Patty Douglas, Re•Storying Autism is a participatory action research creation project that works with people living with autism, or who have attracted the label, and with family members, teachers, former ABA² practitioners and leading scholars who take a critical perspective on what autism is – the 'it' of autism. We collaborate with those who take an interest in how to work in respectful, justice-seeking ways with people living with that which the dominant culture calls autism. Ours is a cross-Atlantic project that brings together scholars and community members in England with those situated in Canada. We're building a film archive. We've gathered beautiful stories – insightful, nuanced, thick, layered understandings of people's experiences of autism that push back against conventional framings. These stories capture and animate people's embodied and embedded experiences as well as the experiences of critical allies.

David: Thank you for that wonderful introduction and context setting. Before I ask any questions, Patty could you respond to Carla's introduction?

Patty: I come to this work in multiple ways. I'm the mother of a son who attracted the label of autism, I was a public-school teacher for almost 10 years in special education, and now I'm a researcher. What strikes me is how the deficit perspective on autism really shapes the way practices of all kinds are enacted. I'm really excited about creating alternatives, because as a mother, teacher and researcher I hear so much educational trauma. I see families struggle with feelings of hopelessness in relation to receiving an autism diagnosis in their family. What I really want to do, and what I think we are doing that is gaining ground internationally, is opening the meaning of autism and the narratives that surround autism beyond deficit. Dominant narratives flatten the experience and make it very thin. We want

to open the possibilities for understanding the 'it' of autism. Not only narratives of neurodiversity, but holding open all possibilities, so people can tell multiple stories that open different possible ways of relating with difference. This year (2021), we shifted our work online and are holding storytelling workshops with Indigenous and settler co-creators in Canada and New Zealand. Autism has been underdiagnosed and mislabelled in Indigenous communities. It's overlaid with Western deficit understandings of difference and culturally insensitive or harmful services. Often, there are no services available at all for Indigenous families in their communities. The storytelling workshops enact a different way to be together – how to be together in difference. This not only extends understandings of what autism can be, but informs practice in affirming ways. And there are wider implications for critical leaders, which is also core to this work.

David: I'm particularly interested in how your explorations can provide different options for practitioners in these contexts who may feel limited by dominant deficit understandings. It's great to find and share hopeful stories from people who are doing things differently. In reading your recent article (Douglas et al., 2021), and from how you have just spoken, I appreciate the exquisite care you are taking, and rigorous thinking you are engaged in. I'd like to enquire about three particular realms. First, there are the principles that are guiding your work, and the care you take with language; then there's your practice of bringing people together in storytelling workshops, and what's really working in those spaces; and, finally, I'd like to hear more about the film archive and how you're using those preferred storytellings to generate new understandings. I'm also keen to ask what ideas you have about what might be useful for practitioners – any stories of practice or ways practitioners could use your films – which might influence people's micro-practices. What you're doing is fantastic and so crucial because sometimes practitioners find themselves co-opted by understandings that invite the use of narrative practices in ways that reify

norms, which is very problematic. And there are loved ones who fear, or are despairing about, what their children and young people are being restricted by – how they're being interpreted. I'm interested in understanding how to respond to the genuine struggles people have, and not diminish those, but in ways that are not reifying of normative judgements.

Patty: I think the main principle that guides this work is the disability studies principle of 'nothing about us without us', and that's done in a collaborative sense. I think what's different about this project, maybe its signature, is that we're bringing together all the different stakeholders or interested groups: family members, teachers, practitioners – everyone who cares about autism. There can often be tensions across groups, so it's not only about including autistic people, but also family members and others who care so deeply about a more just world with and for autistic people. We're not all going to agree, but what we do agree on and what guides us is that we care about people who have attracted an autism label, and we care about disability justice in the world. We ask ourselves how we can hold space for new stories that offer a different narrative, and how those stories resonate with each other across different positionalities. Under the pandemic conditions of COVID-19, autistic artists, co-researchers and critical allies have come together on the Re•Storying Autism project to plan creative research online. Self-named 'the collective', this group initiated a new form of storytelling: a zine-making project called 'Autistic, Surviving and Thriving under COVID-19: Imagining Inclusive Autistic Futures'.³ The collective exemplifies the principles of collaboration and leading with difference, or 'nothing about us without us'.

Carla: Much of our work is conducted in conjunction with the Re•Vision Centre for Art and Social Justice, a centre located at the University of Guelph, which has a mandate to use arts-informed research methods to foster social wellbeing, equity and justice.⁴ In all of the centre's work, we embrace the principle of leading with difference (Rice & Mündel, 2018); for the

Re•Storying Project, this means working collaboratively with autistic people and ensuring autistic experience stays at the centre, including in the design of workshops and in our academic writing together. In our recent co-authored paper, you can't tell the autistic from non-autism-identified contributors. We intentionally blurred the boundaries around expert and subject by approaching everybody's contributions as valued and as situated, and by recognising embodied knowledge as a significant, real, material and important form of knowledge. Another principle of our work at the Re•Vision Centre involves welcoming the disruption that disability and bodymind difference make (Rice & Mündel, 2019). Rather than orienting toward disruption as something to suppress or contain, we orient toward disability's disruption as a moment of learning, and an invitation or pathway to rethinking our practices, including our terms of being together as a group.

Patty: Yes, that segues into what we're doing in the workshops and how we're coming together there. In addition to disruption, I would add 'failure' as a central principle around which we come together in the groups. For the storytelling workshops, I think very carefully about who's in the room together, and interview people before the workshops about what story is most compelling for them and what they need in order to access the space. This doesn't always work, but when it doesn't we think through the ways it's not working in the storytelling space.

A recent example is a workshop I led where one storyteller needed to spread out in the space and take up a lot of room. As an artist, he had brought along artwork and so really needed to take up that space. Another storyteller needed dedicated space and order, and to not have everybody's stuff in their way. So there was a point of tension that resulted in one storyteller leaving for the day. The next day, I sat in the space and really thought through what was needed for this storytelling to co-occur. I reorganised the physical configuration of the space and held conversations with the storytellers. Happily, they still came the next day.

Carla: This is premised on the larger understanding that accessibility, and what makes a space, process or technology accessible, cannot be fully accounted for through a checklist approach. In other words, no space, process or technology will be equally accessible to everyone. This means that accessibility can't be fully standardised (as the checklist approach assumes). Universal design is an important idea(I), but I would argue that it is also a horizon, and people must continually strive towards recognising that, like a horizon, it will continually shift and will never be fully reachable. While we strive toward making our spaces, technologies and processes accessible, we also accept that accessibility is iterative, and that we need to work with the requirements of the people we want to anticipate and centre in the creation of the space. The interviewing Patty did beforehand was critical to thinking through the accessibility requirements of those with whom we designed the workshops. But no-one can anticipate everything, which is why disruption and failure are important parts of the process. Working with failure and flipping it, as Patty did, is a way to materialise and operationalise accessibility as iterative. We try to anticipate and create a welcoming space, but recognise failure as not only inevitable but necessary for all of us to learn what is needed to set, or re-set, the terms of our being together.

David: I really appreciate how you named that, whether talking about the authors of your article or the people coming to the workshops, you're not necessarily sharing the same ideas, perspectives or understandings of autism, but you are sharing that autism and the experience of autistic persons matter deeply to you. Can you say a little more about how you build that sense of *communitas* around that one thing? I know it's not uncomplicated to create a space where people with diverse views can stay together. You mentioned the interviews beforehand, and your considerations about continually creating an accessible space where people can perform the themes most important to them, which are fantastic practices of care and thoughtfulness. Is there anything else you do, before or during the workshops, that

acknowledges the differences, diversity and even disagreements, but still enables people to come together on the theme of caring deeply in relation to the realm of autism and people linked with it?

Patty: I take great care about building and nurturing relationships with autistic activists, and with family members, outside and during the workshops. It's not just a one-off of going in, getting these stories and the relationship is over. There's a relationship that precedes, and a relationship that continues, flattening the hierarchy of governance as much as possible and broadening the researcher collective to include folks that are not necessarily formal collaborators on the project. Making community links does a lot to inform and cradle the workshops. The project began in 2016. Many of the original participants continue as collaborators, co-authors or members of the collective or keep in touch in other ways.

Carla: This is a bit of a tangent, but one of the things that I really like about our co-authored paper is the idea that we have to keep the meaning of autism moving. This orients us to a more processual, moving, evolving understanding that doesn't fix or reify autism as any one thing. People can come with their own beliefs and leave with their own beliefs. We share an openness to each other's perspectives, and a desire to neither fix nor reify. People might have strong ideas about what autism is or means for themselves, but they do not impose that on anybody else. We enter the space and work together in a spirit of openness to one another.

Patty: What comes to mind are the moments when I'm facilitating and holding space for a strongly felt idea or response across tensions. I try to acknowledge the tensions in the room; they're not personal but are related to the material structures and differences people are living with outside the workshops. When tension does occur, which it does, it has a meaning that the project understands in a generative sense. I feel very tangibly when I'm facilitating that there's a holding of that space, a holding open of the meaning of autism, allowing

space for difference. I think the story-making process itself, which is creative and generative, also allows us to appreciate across difference in a way that some other approaches or orientations might not.

Carla: Across workshops focused on a range of issues, I always notice when we move from talking about dominant discourses surrounding the topic, away from a more intellectual conversation and critique, to a more creative process, the energy in the room shifts. People tend not to get mired in identity politics, or get fixed into certain positions, but open up to curiosity, imagination and generativity as they move from the critical to creative mode.

David: Could you say a little more about getting into that mode, and the process of story-making?

Carla: In the Re•Storying Autism project, Patty does all the interviews with potential participant-creators, so they have a good sense of the process prior to entering the workshop space. There's the huge care we take in thinking about the space and the process: led by difference, we decide how to organise the space physically, what objects we should include in the space, who should lead the workshops, which artists and videographers we should hire to support the participant-creators in making their stories, et cetera. It's very, very important to ask what sort of space is friendly and welcoming for people who have attracted an autism label. That won't be one thing or the same thing for everybody, but we take steps and strive as autistic and non-autistic people working together to create an affirmative space, which Patty has supported in a beautiful way. She starts the workshops with an overview of dominant narratives and dominant representations of autism; not an overly academic or theoretical talk, but a straightforward discussion using media examples that speaks transparently about keeping our understanding of the 'it' of autism moving, and not getting mired in 'the truth' of autism, but focusing on what people require in order to live a good life. So, moving away from fixing or uncovering the truth, and toward thinking through how we might re-imagine the world, at least in

the space of these three days, and asking how we can create a world where autistic difference is anticipated, wanted and has a place (Rice et al., 2021). That's our starting point.

David: Fantastic.

Patty: It's important that all bodies and movements are welcome in the workshop space, including the use of stim toys or gadgets, coming in and out of the room and participating in non-normative, non-typical or non-interactive ways. If we're having a story circle as part of the workshop, it doesn't need to be in the shape of a circle where everyone speaks in turn; it can be whatever is most comfortable. People have participated by cordoning off part of the room to make it comfortable for themselves or by sitting on the floor. If we ask someone to speak, they may prefer to write something. We welcome all ways of communicating, all kinds of movement, especially around stimming and the use of gadgets, because that has often been what folks who've attracted the label of autism are asked *not* to do. You know, 'quiet hands' and other behaviourist training family members, teachers and autistic folks are subjected to in such an intensive way and in so many different parts of the world. It's a real opening up to difference as fundamental to the world. We also have a quiet room where participants can work.

Carla: Patty organises the chairs in the space, so people don't necessarily have to sit in a circle. People can sit in the ways that they want in the space, and they do because she really does set that tone from the very beginning.

Patty: I've come to look at it more as a 'story scatter'.

David: I like it!

Patty: Then it goes in all directions, right? I want to honour that the circle is often understood as very inclusive, but it isn't for everyone. There's some interesting friction between different understandings of the meanings of circles, but scattering keeps the meaning of things open. One storyteller did most of

his participation from the quiet room, which also has low lighting. We filmed some of the large group activities so he would have virtual access, and so participants didn't need to be in the same timeframe. He participated almost entirely from the quiet room and just came to bits and pieces of the workshop with the whole group. He sent a follow up email, probably eight months later, saying he'd never felt such a sense of belonging. Access can look different, and it's up to the team to challenge the normative expectations we bring, even as people who think about this all the time. I have to remain open to being constantly surprised and challenged, which I think of as part of the disruption Carla mentioned.

David: I love that story.

Carla: We have a very highly trained team of videographers, and both technical and artistic team members who can support the storytellers in creating their work. Some storytellers draw heavily on the team; others do a lot on their own. It depends on how much prior experience they have with technology, with image and video, and with story. We make it clear that voice is not necessary to tell a story. A story can be told in many different ways. There are examples in the films we link to in our paper. Some people choose to tell stories through video clips, through images, movement, ambient sound or music. There are lots of different ways to tell stories, and we don't want anyone to feel constrained by the notion of story as language and voice.

Patty: We are working with and adapting the Re•Vision method in the Re•Storying workshops. We provide quite a structured schedule for the workshop, which can be a point of tension when some people need the schedule to be exactly on time and others can't meet that expectation. I was able to use Re•Vision's access guide and expand it for the Re•Storying workshops with more images and description, and I give considerable thought to how to orient to time in the workshop, as well as space, because folks need to know what to expect. The reality of the workshops is that they're

not always on the minute. However, we do have a schedule, and that first day I give an overview of what we're *not* doing, such as the dominant story. Then we have the story scatter, where people sketch out the story they most want to tell, and this is done as a whole group. But no-one has to share. Carla could probably say more about how the process helps people develop the story they want to most tell.

Carla: We encourage people to work at the edge of their comfort level, and to push themselves as much as they feel comfortable – to where comfort meets creativity. People are welcome to tell whatever story they want at this moment in time. They may want to story autism, or something about their school experiences. Creators in the workshops have a lot to say about school, about the disciplining and policing of bodies, and of difference at school. School has emerged in these workshops as a particularly potent site where people describe being hurt in profound ways, including and especially through the intense and often violent normalising pressures they are subjected to. Their relationship with schools is complex and contested, and a domain for crafting compelling stories, as is the clinical space. Some people want to tell stories about their experiences of diagnosis, of conventional treatment for autism, or of other experiences involving harm or a complete miss of what they require in order to thrive and feel a sense of belonging. I've gained a visceral experience of the immense pressure that comes from these institutions to construct a 'normal' human.

David: A lot of work goes into that, doesn't it!

Carla: Yes! And millions of dollars, and time and energy that could be much better spent trying to work with people's potential, and how they're responding, connecting and growing. It's hard to think outside of the need to discipline and punish bodies in order to fit a certain definition of the human, and how to move outside of that. I don't think it's any coincidence that some of the strongest advocates for autistic children are mothers

and parents. That, I think, has to do with connection and coming to know one's child in a way that the system doesn't or won't. Observing profound disconnects between what makes that child happy, what helps them flourish, and what the systems are trying to impress on the child or trying to make them become.

David: It makes a lot of sense to me that some of the themes you're mentioning are often the focus of the films or the stories people want to tell. You also mention in your article a love relationship between siblings. Can you say a little bit about that? It sounds like a counter-story that was wanting to be shared.

Patty: Sometimes we think about the stories made in our workshops as telling new love stories, and I think that so often the dominant story around families and siblings is one of being traumatised from having an autistic sibling. I don't ever want to deny that it can be very difficult to live through the stresses a family might be living through, but this story is about this really beautiful intimate relationship that was also disciplined, constrained and violated in so many ways by the larger system – the psy-complex (education, psychology and psychiatry) in school focused on making 'normal' humans. We are writing with our collaborators in the UK about the way this system in schools produces 'madness' and disciplines mothers and families (Douglas, Runswick-Cole, Ryan, & Fogg, 2021). Carla, would you like to say anything else about that beautiful, intimate story?

Carla: Disability and bodymind difference become known in these intimate relationships. Western-world convention is to know difference by trying to construct a notion of what is appropriate, normative or typical for a human being, and from there, attempting to construct an idea of what is 'abnormal' or atypical. So many resources and energies are poured into constructing the typical and atypical – from creating developmental benchmarks to the myriad practices (administering tests, charting behaviour, conducting psychological interviews) people engage in to measure somebody against what they 'should' be. Yet, this

story is profoundly different because it says something about another way of knowing difference, one premised on intimacy and love.

Patty: Those relationships that are marginal to normative ways of understanding are sites of radical knowledge that can push back. These relationships include autistic people themselves and family members; mothers will sometimes perform what they have to in the public realm in order to gain access to certain things, but have this other intimate knowledge, and I think siblings do as well.

David: That's a beautiful segue into what alternative roles practitioners can play to honour these intimate knowledges of mothers and family members, rather than just requiring the sorts of performances they might be making elsewhere. I love the sound of every part of this process and now you have these films, or representations, that are being shared and engaged with to create different spaces and possibilities for autistic people and those who love them. Is there anything you would add about what practitioners could be doing to support autistic people and families and friends in non-normative ways?

Patty: I can speak about my process and Carla could speak about shifting consciousness in relation to what autism can be, which is really important. Practice and consciousness are so linked. One way I'm going about addressing questions of practice is through professional development workshops with teachers and practitioners using the videos from the project, and finding the critical practitioners and educators working in systems who are doing the hard work to actually change processes and practices that are in place, rethinking them; finding the critical leaders who are open to this and to making change. Over the four years I have been leading Re•Storying Autism, I have encountered an increasing openness to shifting understandings of autism away from deficit models and rethinking practice in education, social work, educational psychology and beyond.

Carla: Policy changes are important. For example, in the province of Ontario, there is only one

kind of support parents can get for their autistic children – ABA: Applied Behavioural Analysis. That is the only therapy option. It has another name now—

Patty: Early Intensive Behavioural Intervention. It's very intensive: 40 hours a week starting at age two, trying to teach the child normative behaviours as if that's going to create a normative person.

Carla: You know, all of this is imagined. It's about creating a normative subject who will be a good, productive citizen for neoliberal capitalism. That's the ultimate goal. That's where the funding is and parents have no options, at least not in the Ontario context. It would be fantastic if parents had more options around what kinds of supports they want for their child.

Patty: When I think about the number of practitioners that surround an autistic child, and autism doesn't end in childhood obviously, if those practitioners are changing their own understanding of autism, then that opens up a whole new and hopeful landscape for working with families and individuals. I'm part of the Neurodiversity Network in Ontario, which is bringing together different practitioners, therapists, researchers and social workers to rethink how we might approach practice. I think in teacher education, in social work education, in counselling education and all of those trainings, if we can make the shift in understanding autism differently through the stories we release in the world, then that is the first thing. And policy change.

Carla: Katherine Runswick-Cole is one of the researchers we're working with in England, and her paper on the disability commons (Runswick-Cole & Goodley, 2018) moves away from ideals of the nuclear family towards more social models of care. She's proposing care networks and thinking more broadly about how we organise ourselves in the Anglo-Western world. I'm interested to learn about other kinds of relational ethics and values and kinship ties that perhaps create more of a sense of a commons, or a community care model. Not everybody has inherited this private/

public split where there's only the individual or nuclear family, and the economy, which is what we've learned from the hyper-neoliberalised, Westernised parts of the world.

David: Unfortunately, I think that Western psychology is pretty powerful at travelling and getting its roots into many, many places, as you know. But there are certainly different opportunities in every place for sharing learnings, experiences and creative projects. I also know that narrative practitioners in many different places will revel in what you are doing and could learn a great deal from it, including the storytelling workshop processes. I could imagine those principles being very helpful in working with families, or with schools and practitioners. The ways you bring people together leaving the 'it' of autism open and enabling preferred stories to be told and people to be supported in their preferred lifestyles could really form a framework for practitioners. What you're doing is so needed around the world and is really exciting! Listening, I had a sense of possible freedom – that if some of these rigidities can finally be lessened slightly, what a joyful world we would have.

Carla: So true.

Patty: Yes, really wonderful. I feel quite joyful and free too, just talking about the potential.

Notes

¹ Details of the Re•storying Autism project can be found in Douglas et al. (2021).

² Applied Behavioural Analysis (ABA) is a commonly used 'remedial' approach to autism that is discussed and critiqued in Douglas et al. (2021). Also see Gibson & Douglas (2018).

³ See www.restoryingautism.com/zinemaking-workshop

⁴ See www.revisioncentre.ca/ for more information.

References

- Douglas, P., Rice, C., Runswick-Cole, K., Easton, A., Gibson, M. F., Gruson-Wood, J., Klar, E., & Shields, R. (2021). Re-storying autism: A body becoming disability studies in education approach. *International Journal of Inclusive Education*, 25(5), 605–622. <https://doi.org/10.1080/13603116.2018.1563835>
- Douglas, P., Runswick-Cole, K., Ryan, S. & Fogg, P. (2021). Mad mothering: Learning from the intersections of madness, mothering and disability. *Journal of Literary and Cultural Disability Studies*, 15(1), 39–56. <https://doi.org/10.3828/jlcds.2021.3>
- Gibson, M. F., & Douglas, P. (2018). Disturbing behaviours: Ole Ivar Lovaas and the queer history of autism science. *Catalyst*, 4(2), 1–28. <https://doi.org/10.28968/cftt.v4i2.29579>
- Rice, C., & Mündel, I. (2019). Multimedia storytelling methodology: Notes on access and inclusion in neoliberal times. *Canadian Journal of Disability Studies*, 8(2), 118–146. DOI: <https://doi.org/10.15353/cjds.v8i1.473>
- Rice, C., Riley, S., LaMarre, A., & Bailey, A. (2021). What a body can do: Rethinking body functionality through a feminist materialist disability lens. *Body image*, 38, 95–105. <https://doi.org/10.1016/j.bodyim.2021.03.014>
- Rice, C. & Mündel, I. (2018). Storymaking as methodology: Disrupting dominant stories through multimedia storytelling. *Canadian Review of Sociology*. 55(2), 211–231. <https://doi.org/10.1111/cars.12190>.
- Runswick-Cole, K., & Goodley, D. (2018). The ‘disability commons’: Re-thinking mothering through disability. In K. A. Runswick-Cole, T. Curran, & K. Liddiard (Eds.), *The Palgrave handbook of disabled children’s childhood studies* (pp. 231–246). London, England: Palgrave Macmillan.