



Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.



# Pivotal care practices: Care ethics in inclusive arts-based research with people labelled/with intellectual disability during the COVID-19 pandemic

Erin Kuri<sup>a,\*</sup>, Ann Fudge Schormans<sup>b,1</sup>

<sup>a</sup> McMaster University, School of Social Work, Kenneth Taylor Hall (KTH), Room 319, 1280 Main Street West, Hamilton, Ontario L8S 4M4, Canada.

<sup>b</sup> McMaster University, School of Social Work, Kenneth Taylor Hall (KTH), Room 319, 1280 Main Street West, Hamilton, Ontario, Canada

## ARTICLE INFO

### Keywords:

Intersectionality  
Disability justice  
Care ethics  
Arts-based research  
Inclusive research  
Intellectual disability

## ABSTRACT

In this article, we aim to illustrate how inclusive research can be situated as a form of care work. We do this through addressing tensions and possibilities arising in an ongoing arts-based community-research project – *DiStory, Then and Now*. We discuss the design of the project along with critical, philosophical, and ethical foundations that drive decision-making and shifts in methodology in response to COVID-19 pandemic restrictions. We argue that understanding inclusive research as care work is vital, particularly in pandemic times where complex socio-political contexts threaten the social survival of individuals and communities that have traditionally been excluded from knowledge creation projects. Our efforts to counter epistemic violence through practices of care are critically considered alongside tensions emerging in connection with physical contact restrictions combined with technology barriers experienced by many of our group members.

## Introduction

In this article, we discuss the practice of inclusive research as a form of care work that aims to counter epistemic violence imposed on people labelled/with intellectual disabilities.<sup>2</sup> We aim to demonstrate the importance of inclusive research practices in alignment with critical feminist values of intersectionality, disability justice, and ethics of care, and how such practices can be applied within arts-based research by creative arts therapists and other interdisciplinary research teams. To do so, we will share an example of a community-based research project called *DiStory: Then and Now*.<sup>3</sup> Through this example, we illustrate how inclusive research can be understood as a practice of care. We share this

example because it allows us to convey how inclusive research principles can be applied under ideal conditions, as well as less-than-ideal conditions. We examine our research practices and ways we had to change our methods (described as *cripping*) in less-than-ideal conditions, prioritizing care despite shifting circumstances relating to social restrictions during the global pandemic.

### Distory project

*DiStory: Then and Now* is an inclusive community-based project, rooted in critical disability studies, involving elements of research through knowledge sharing and building practices, however, not all

\* Corresponding author.

E-mail addresses: [kurie@mcmaster.ca](mailto:kurie@mcmaster.ca) (E. Kuri), [fschorm@mcmaster.ca](mailto:fschorm@mcmaster.ca) (A.F. Schormans).

<sup>1</sup> ORCID: 0000-0002-7892-3599

<sup>2</sup> There is no universal understanding or experience of *disability*, the words used to talk about disability shift and vary across space and time (Titchkosky, 2001). Amongst people identified/diagnosed with *intellectual disabilities* – including *DiStory* project members identified with intellectual disabilities – not all accept the label, nor do they all define themselves using this language (Logeswaran et al., 2019). In this article we use the political term *people labelled/with intellectual disabilities*. The slash between the words *labelled* and *with* recognizes that while some people may claim this label, others understand the label to have been imposed upon them (McClelland et al., 2012), identifying this imposition as a practice of oppression that works to *disable* them (Titchkosky, 2001).

<sup>3</sup> In 2009, the province of Ontario (Canada) closed the last of its large Regional Centres (institutions) for people labelled/with intellectual and developmental disabilities. Extant and emerging research has revealed the atrocities that occurred in these institutions: experiences of neglect, physical, emotional and sexual abuse, violence, exploitation, and lack of education and care. A class action lawsuit by survivors of Huronia Regional Centre, led to a settlement and apology from the Ontario government, and was followed by additional class action suits from survivors of other regional centres. Funding for *DiStory* resulted from the Huronia class action lawsuit. A number of groups (academic, community, mixed) across the province received funding for projects that support survivors in various ways, including the gathering, preserving and sharing of their stories to ensure this history is not forgotten.

activities of the project involve research. Nor is it an art therapy study, although we do engage in visual art making as a means of supporting inclusion, access, and knowledge sharing towards social change. Talwar's (2019) articulation of the use of the arts in activist and community contexts resonates with us. She highlights the following:

artists, activists, and cultural workers have used arts-based methodologies to demonstrate the link between critical inquiry and praxis when critiquing the social and personal consequences of violence, trauma, shame and stigma. I contend that when affect, memory, and feelings become the subject and method of analysis, feelings can be something useful in creating spaces for expression, creativity, and hope. When art links trauma, the body, feelings, memory, affect, and subjective formation to the social construction of race, class, gender, sexuality, or disability, it encourages an analysis of power relationships to question the status quo with the aim of transforming relationships (p. 38).

The DiStory group is composed of four academic co-researchers, three academic research assistants, a community-based co-researcher, an arts facilitator, and a graphic facilitator (identifying with and without disabilities). Group membership also includes fourteen co-researchers labelled/with intellectual disabilities, including people who are survivors of large-scale institutions for people so labelled, as well as a younger generation of labelled people who did not grow up in institutions but continue to experience institutionalized forms of care and ableism. At the request of group members labelled/with intellectual disabilities, we are developing curriculum materials to facilitate post-secondary students' learning of these histories, and to make them aware that the closure of large-scale institutions has not meant the end of ableism, exclusion, violence, and institutionalized care for people labelled/with intellectual disabilities.

Our project is ongoing, continuously (re)shaped through collaborative planning to adapt to existing and emerging pandemic-related social circumstances. This article is not framed as a traditional presentation of the overall project, methods, analyses and findings. Rather we share our rationale for how the project has been designed as a form of care work and the critical, philosophical, and ethical foundations driving decision-making and the directions taken to shift our methods in response to pandemic restrictions, while continuing to centre the needs and goals of our most marginalized project group members: members labelled/with intellectual disabilities.

### Background of authors and contribution to the creative arts therapies

The professional field of art therapy, like other modalities of creative arts therapies, was established as a mental health profession, shaped by interdisciplinary theories and practices from fields such as medicine, behavioural sciences, the arts and education (Yi, 2019). It has traditionally been aligned with a medical model of care focusing on practices of assessment, rehabilitation, progress and cure (Yi, 2010). Kaplan (2002) highlights how leaders and educators in the field have tended to belong to dominant identity groups with respect to class, race, and ability. Art therapy has been critiqued by disability arts activists and scholars for prioritizing individualized pathology over social and political matters in the lives of disabled people (Miller et al., 2020; Yi, 2019). Although art therapy researchers have engaged in research with communities labelled/with intellectual disabilities (Lister et al., 2009; Schrade et al., 2011; Trzaska, 2012), there are few directly named collaborative or inclusive approaches to research conducted by creative arts therapists. Self-identified crip artist, activist and art therapist, Chun-Shan Yi (2019), cautions art therapists not to engage in practices that reinforce stereotypes and ableist social norms that position disabled people as vulnerable, helpless, in need of rehabilitation or rescue. Miller and colleagues (2020) urge art therapists working with people labelled/with intellectual disability to attend to matters of autonomy,

reciprocity, and flexibility in space-time ways of engaging. They call for greater collaboration with this group in inclusive approaches to research and practice, shifting dominant narratives about disability and transforming relational dynamics of power. In this article, we share ways that these goals can be supported through inclusive and collaborative approaches to arts-based research.

As authors of this article, we collaborate and contribute perspectives from interdisciplinary fields of study and professional practice. We view interdisciplinary collaboration to be an important opportunity for dialogue and transformation, mitigating some of the areas of risk identified within the art therapy literature in connection with research conducted in the area of disability. We believe the combination of our perspectives to be relevant to the field of creative arts therapies, bridging knowledge about creative process with ways of engaging in research informed by critical feminist and critical disability theory. Erin Kuri (gender pronouns she/her) is a fifth year PhD candidate in Social Work and Gender Studies. She holds a master's degree in creative arts therapies, specialized in art therapy and has 15 years of practice and teaching experience as a community-based art therapist. As an academic research coordinator/co-researcher, she contributes her skills and insights to the collaborative work the DiStory project is undertaking. Ann Fudge Schormans (gender pronouns she/her), is an academic, principal investigator/co-researcher of the DiStory project. She brings a long history of social work practice, community advocacy and activist work, and inclusive research experience with people labelled/with intellectual disabilities to the collaborative<sup>4</sup> work of DiStory. Drawing on a critical disability framework, her inclusive research engagements employ a range of arts-based methods.

### Epistemic injustice experienced by people labelled/with intellectual disabilities

People labelled/with intellectual disabilities have historically been objectified, exploited, exposed to violence, and excluded within the context of research through disciplines such as education, psychology, social work, biology, and medicine (Clare, 2017; Nielsen, 2012; Trent, 1994). Walmsley (2001), a historian of learning difficulties in the United Kingdom, documents that "The field has been dominated by eugenics, psychology, educational studies, and medical investigations, in which people with learning difficulties<sup>5</sup> were tested, counted, observed, analyzed, described and frequently pathologized, but never asked for their views" (p. 188). Consequent to ableist assumptions of (in)ability, the ideas and perspectives of people labelled/with intellectual disabilities have not traditionally been incorporated into research practices (Fudge Schormans & Chambon, 2012).

The work of Amanda Fricker (2007) examines relationships between themes of social power and knowing. Fricker coined the term *epistemic injustice* to describe "the wrong done to someone specifically in their capacity as a knower" (p. 1). In the presence of social power and identity prejudice, marginalized speakers are often silenced, discredited, and deprived of opportunities to collectively make meaning of shared experiences and knowledge (Fricker, 2007). Fricker emphasizes that "any epistemic injustice wrongs someone in their capacity as a subject of

<sup>4</sup> A collaborative model of inclusive research with people labelled/with intellectual disabilities respects the right of all project members to participate in those aspects of the project that they wish to, in the ways that work best for them. Roles and responsibilities may shift across the project and are negotiated as a group (Bigby et al., 2014a, 2014b). This includes participation in dissemination activities such as the writing of articles. This is the approach taken in DiStory. While researchers labelled/with intellectual disabilities did not co-author this article, they have co-authored other pieces (one in-press, one under review) emerging from the work thus far.

<sup>5</sup> *Learning difficulties* language, as opposed to *intellectual disabilities* language is used in the UK.

knowledge, and thus in a capacity essential to human value” (2007, p. 5).

Prior to the pandemic, all DiStory group members gathered together several times in an accessible community space, to collaboratively design and begin the project. In these workshops, as a group, we determined the focus of the work, how to share our experiences and knowledge safely and what was required to do so. We also discussed how we would support each other in what we anticipated would include difficult conversations (e.g., having a social worker not attached to the project attend workshops to provide support as needed). We determined ways of working collaboratively and, again, safely (e.g., checking in as a group at the start and close of each workshop; being open to people participating in fluid ways), and how decision-making would occur (working towards consensus amongst the larger project group for decisions regarding project goals, aims and practices and within smaller groups working on creation of different curriculum materials). Identifying a number of different curriculum materials to develop, each group member chose which activities to participate in. Within these smaller groups, initial roles and responsibilities were negotiated, and discussions begun as to ways of creating curriculum materials that would support project goals of working towards social justice and social change. Designed as a collaborative inclusive project and rooted in a critical disability studies framework, co-researchers labelled/with intellectual disabilities are thus integral members of the project. While all group members contribute to discussions, sharing their own perspectives, experiences, and asking questions to further and deepen conversations, the DiStory project actively seeks out and centres the knowledge and experience of people labelled/with intellectual disabilities (Walmsley & Johnson, 2003) to push back against their long-standing exclusion from the production of knowledge about *intellectual disability* and the lives of people so labelled.

In what follows, we share an overview of inclusive research, followed by ways in which inclusive research aligns with critical feminist theories of intersectionality, disability justice, and ethics of care. We discuss intersectionality theory as it relates to disability and disability justice. We explore inclusive approaches to research in connection with disability justice and ethics of care. Positioning inclusive research as care work, we illustrate how these principles and practices can be applied through an example of an inclusive arts-based project in practice: DiStory. Participatory and inclusive research practices have come under fire with concerns being raised that such practices may inadvertently reproduce the exclusions and power imbalances they meant to challenge. We share tensions and possibilities in connection with reflexive adaptations our group had to make across our project and research practices during the COVID-19 pandemic, while aiming to sustain our values and commitments to inclusivity, collaboration, and epistemic justice.

### **Inclusive research methods with people labelled/with intellectual disability**

Inclusive research with people labelled/with intellectual disability is a political practice with aims of centring the knowledge and experience of people labelled/with intellectual disabilities, disrupting power hierarchies, and the democratization of knowledge production. In this section, we elaborate on what we mean by *inclusive research*. We encourage arts-based researchers and arts-based practitioners to consider how they may apply inclusive approaches in their work with people labelled/with intellectual disabilities.

#### *What is inclusive research?*

The term *inclusive research* was coined by Jan Walmsley, a historian of learning difficulties, in 2001 to describe research methods that centre the interests and involvement of people labelled/with intellectual disabilities (Walmsley & Johnson, 2003). Kelley Johnson is a scholar of

disability, policy and practice. Walmsley and Johnson (2003) describe feminist research, participatory action research, and conceptual shifts across qualitative research involving power relations, to be significant influences on the development of inclusive research methods. These shifts also reflected a break from practices of institutional segregation of people labelled/with intellectual disabilities (Walmsley & Johnson, 2003; Yi, 2019), and their marginalization as knowers (Fudge Schormans & Chambon, 2012). The inclusive research movement began in the UK in the 1980s, as ways of working with people labelled/with intellectual disabilities in knowledge building contexts grew, reinforced by ethics, government, and funding bodies (Walmsley & Johnson, 2003). Inclusive research is currently more fully established in the UK than in Canada.

The term *inclusive research* encompasses a range of approaches such as participatory, emancipatory, or action-based, in which people labelled/with intellectual disabilities are actively involved in research processes and knowledge production (Walmsley, 2001). Participatory research approaches emphasize the formation of research partnerships with non-academic community members across the research study design, focusing on a problem identified by the community (Leavy & Harris, 2019). Action-based approaches aim to bridge divisions between theory, research and action (Leavy & Harris, 2019). Emancipatory research approaches (more currently referred to as transformative research), aim to address social justice and human rights with respect to individuals and communities historically excluded from research practices, extending values of inclusion through the development of partnerships (Leavy & Harris, 2019). These three research approaches are sometimes understood to share the same values and practices and sometimes understood as different approaches to working with marginalized communities.

While practiced in many different ways, Bigby and colleagues (2014b) assert that inclusive research projects tend to fall into one of three approaches, each varying in degree and forms of participation. In the first approach, people labelled/with intellectual disability are involved as leaders of the project – initiating the project, having control of the funding, research design and completion. In the second approach, people labelled/with intellectual disability act as collaborators or co-researchers, working alongside non-labelled academic and/or community-based researchers. Collaborative models recognize the value of the different contributions that *all* participating researchers bring to the work, and was the model employed in the DiStory project. In the third approach, people labelled/with intellectual disability work as advisors to the project, having less control and active involvement than in the other two approaches. Inclusive research is “research in which people with learning difficulties are involved as more than just research subjects or respondents” (Walmsley, 2001, p. 187). Positioned as change agents, their inclusion aligns with emancipatory and action research approaches, reflecting overarching goals of social change, of justice (Ignagni & Fudge Schormans, 2016; Runswick-Cole & Goodley, 2015) and the potential of inclusive research to be a catalyst for resistance, for action – even activism – towards change (Fudge Schormans et al., 2019).

Opposing the ableism inherent in traditional research methods, the meaningful inclusion of people labelled/with intellectual disability in research can be understood as a political practice, a matter of disability and human rights, that works to counter the epistemic exclusions and injustices wrought by disabling discourse as to who is/is not a researcher, whose knowledge does/does not count (Fudge Schormans & Chambon, 2012). This repositioning as knowers (in their own eyes and the eyes of others) can be disruptive for audiences of the work (Fudge Schormans et al., 2019). Potentially more disruptive, is their repositioning as adversaries, when their perceptions contradict and challenge dominant deficit-based understandings of *intellectual disability* and people so labelled (Fudge Schormans & Chambon, 2012). Claiming this right to be included, while deepening and expanding meanings of *intellectual disability*, people labelled/with intellectual disabilities have made plain that they have much to bring to non-disabled people’s

understanding of intellectual disability, and to the doing of research (Fudge Schormans & Chambon, 2014).

#### *Inclusive research: crippling research methods as care practice*

McRuer and Wilkerson remark that “A queercrip consciousness resists containment and imagines other, more inventive, expansive, and just communities” (2003, p. 7). Acknowledging the heterogeneity of people labelled/with intellectual disabilities, inclusive research endeavours to support varied forms of participation and contributions, and requires an openness to multiple and shifting processes, roles and responsibilities for *all* researchers involved in an inclusive project (Bigby et al., 2014b). Attending to “how participation and collaboration are enacted and how power is embodied” (Bain & Payne, 2016, p. 332), it works towards democratizing research by working with people to establish practices that effect a more equitable distribution of power between researchers with and without disability. In this way, inclusive research is aligned with practices of *cripping* research.

The practice of *cripping* can be understood as a critical strategy influenced by academic queer studies, originating through arts-based disability activism (Lewis, 2015). *Cripping* aims to critique, render visible, and challenge compulsory able bodied/minded assumptions of normalcy and deviance that manifest in everyday representations and practices (Kafer, 2013; Sandahl, 2003). Acknowledging ways in which disability acts as an invitation to imagine otherwise (Eales & Peers, 2021, p. 164), inclusive research practices make space for and supports different ways of being, knowing, participating, and doing that disrupt and push against ableist/sanist values and priorities inherent in research privileging an autonomous normative-bodied/minded subject. Disability then is a “methodological intervention”, it “crips methodology” (Price & Kerschbaum, 2016, p.20). For DiStory, *cripping* research means positioning co-researchers labelled/with intellectual disabilities as leaders in determining project goals and processes, changing methods to be inclusive of labelled co-researchers, committing to epistemic justice and valuing their human rights to active citizenship as knowledge holders and makers. Alternative ways of communicating, collaborating in accessible spaces, and planning across time are valued and supported. An appreciation for fluidity is ingrained in the research design, the methods used, with an understanding that plans, activities, and roles, may shift and change. Matters of access are considered, such as arranging transportation, creating plain language reading materials, and engaging the use of a creative arts facilitator. Inclusive researchers work collaboratively, with an intentional attitude of openness.

#### **Alignment between inclusive research, intersectionality and disability justice**

We understand the overarching values and principles of feminist intersectionality theory, as well as those of disability justice, to be central to the work of inclusive research. In this section, we provide an overview of feminist intersectionality theory. We discuss concepts that support understanding of how individuals who straddle multiple forms of marginalized identity are situated in complex contexts, with particular attention to relational dynamics of interlocking power and oppression.

The convergence of the civil rights movement, disability rights movement, women’s liberation movement, and labour movement occurred within industrialized nations between the 1950s and 1980s. Language and ideas formed through these movements contributed to visibility and intelligibility of experiences of social oppression (Hill Collins & Bilge, 2016). Kimberlé Williams Crenshaw, a Black feminist legal scholar, coined the term *intersectionality* in 1989 to critique how single-axis identity categories were often applied in human rights cases that attended to anti-discrimination. Crenshaw argued how focusing on only one aspect of identity at a time, rendered invisible the ways that multiple axes of identity could co-constitute experiences of social

oppression in particular contexts (1989). She specifically drew attention to ways Black women experienced discrimination within social contexts that privileged being both white and male. If only one identity category was examined, there were some cases that found that no discrimination took place. If, however, one analysed the ways discrimination took place as a result of intersectional aspects of identity, in relationship with an analysis of power dynamics, these cases could be claimed and injustice addressed (Crenshaw, 1989). Cooper (2016) notes that intersectionality theory has been influential in movements to re-examine social policy and critical ways of thinking about the construction of societies from a more complex understanding of identity and lived experience. It has also contributed to a shift away from essentialist notions of identity in connection with gender, race, ability, class, age, and sexual orientation, recognizing the individual differences, complexities, and overlaps within identity sub-groups. Feminist disability scholars Garland-Thomson (2005) and Kafer (2013) explore intersectionality within the context of disability, tracing how socially constructed stories and visual representation of disability and embodiment evolve across time and space, shaping how individuals and groups experience equity and inclusion in their day-to-day lives. Employed as an analytic tool, intersectionality theory is a means of gaining insight into how policies and practices across complex contexts entwine with relations of power and material outcomes for individuals and communities. Six core concepts are often present in instances when intersectionality is used as an analytic tool: social inequality; power; relationality; social context; complexity; and social justice (Collins & Bilge, 2016). We next explore how these concepts are reflected in the Disability Justice movement.

#### *Intersectionality and disability justice: centering marginalized perspectives*

Disability Justice can be understood as a political movement, a framework, a culture, a vision, and a practice (Berne et al., 2018; Piepzna-Samarasinha, 2018). Created by disabled Black, Indigenous, and People of Colour queer femmes, it aims to centre the lived experiences of those most marginalized within the broader disability movement (Piepzna-Samarasinha, 2018). Importantly, people labelled/with intellectual disabilities have largely been excluded from mainstream North American disability activism, which has tended to centre those living with physical impairments (Kröger, 2009). Patricia Berne, with Aurora Levins Morales and David Langstaff, and on behalf of Sins Invalid (2018) share ten key principles of Disability Justice: intersectionality; leadership of those most impacted; anti-capitalist politic; cross-movement solidarity; recognizing wholeness; sustainability; commitment to cross-disability solidarity; interdependence; collective access; and collective liberation.

When we asked all DiStory members what Disability Justice meant to them, responses highlighted the importance of equity and inclusion, participation and accurate representation, the incorporation of relational care practices that honour autonomy, attention to the historical legacy of intellectual disability, goals of social change in the interest of the disability community, and recognition that survival depends on society conceptualizing people labelled/with intellectual disability as human and worthy of care and respect. Nicholas Herd describes that “disability justice means that we are fighting for disability rights. We are fighting for our voice to be heard more.” Bill Chase explains “you have to tell your story to help them understand.” Marie Slark bridges the theme of autonomy and inclusion through her statement that people must be given “the right to live our lives the way we want to live them. To be treated like everybody else.” Richard, declares “it’s important for their life.” These statements clearly reflect values of intersectionality and disability justice with respect to social justice, inclusive leadership, interdependence, and collective liberation. Cognizant of long-standing and tenacious exclusions and inequalities in the lives of labelled people, DiStory members highlight the crucial importance that people labelled/with intellectual disability be included in every stage of the research process that aims to work towards changes in their lives.

As a group, we appreciate that social justice is experienced differently by everyone and that such an aim can never be fully achieved. No single project can effect significant change, but can work towards such. A message shared by many DiStory members is that you have to teach people in order for change to happen. Group members labelled/with intellectual disability must teach non-disabled people about the legacy of institutionalization and the ways this legacy continues to impact current contexts. Following Piepzna-Samarasinha's (2018) expression of radical positionality regarding carework within disability communities, we see DiStory as radical because it creates and is a space for people historically stigmatized and silenced to share their stories and act within the position of knowers and educators. We acknowledge how radical positionality manifests across sub-groups within disability communities, and how care work is carried out, depends a great deal on our privilege to organize as a community and freely communicate. This means having access to technology and technology literacy; the nature of interdependent relationships between disabled and non-disabled community members; and how an event such as the pandemic can make such privilege precarious.

In the following section we discuss how inclusive research can be understood as a practice of care, in alignment with values and principles of feminist care ethics.

### How inclusive research can be understood as a practice of care

In this section of the article, we aim to demonstrate the relationship between ethics of care and principles of inclusive research approaches, supporting the reader to appreciate how efforts made within inclusive research can be conceptualized as care work. What do we mean when we discuss the concept of *care* or *care practices*? To piece together the notion of care, we draw from the work of Joan Tronto and Bernice Fisher (2013). In Tronto's book titled *Caring Democracy* (2013), she presents five *Steps in the Process of Caring*. The five steps include: "caring about; caring for; caregiving; care receiving; and caring with" (p. 22–23). The first step of caring, *caring about*, is an act of noticing when care needs require someone to meet them. *Caring for* is the action of taking responsibility to address the identified need(s), while *care-giving* is conceptualized as the process of carrying out the care giving work. *Care-receiving* is presented as the act of observing the care recipient's response and that the care giver then makes a judgment about that response (such as assessing if the practice met the need). Finally, *caring with* is framed as the act of ensuring that the process of caregiving is consistent with aims of democracy, and commitments to social justice, equality, and freedom for everyone. Importantly, these care steps are being enacted by all DiStory members in various ways throughout the project with different people at different times. For example, during the sharing of difficult stories, as well as recognizing and attending to others needs during the pandemic.

In this article we pay particular attention to the fifth step: attending to democratic justice, equality, and freedom in relation to inclusive research practices. Our decision is informed by knowledge of the many violent and oppressive practices that have and continue to be imposed upon disabled persons in the name of *care* (Clare, 2017; Eales & Peers, 2021; Piepzna-Samarasinha, 2018). The practice of care in all its forms – who is cared for, how and by whom – typically reflects societal values and, by extension, the (de)valuation of particular groups of people. Many people labelled/ with intellectual disabilities share the disability movement's critique of accepted notions of care, and associated devaluation of disabled people and disabled lives. For them, *care* far too often *hurts* – emotionally, physically, and in other material ways (Fudge Schormans, 2015).

Walmsley and Johnson (2003) describe five components of inclusive research that we consider alongside the work of Tronto and Fisher (Tronto, 2013) in thinking about inclusive research as a practice of care (components we regard as foundational to DiStory). The first is that people labelled/with intellectual disability have ownership of research

questions; second, the process and outcomes of the research benefit their interests – and they are the ones to make this determination; third, research processes and activities are collaborative and inclusive of disabled people – on their own terms; fourth, people labelled/with disabilities have some degree of control through carrying out the research process and disseminating the findings; and fifth, research materials, processes and findings are shared in an accessible manner.

In our efforts to engage in care work through our practices in DiStory, we aim to counter epistemic violence. As noted earlier, flexibly moving through the various stages of our work we collaborate as a group to make decisions, honouring values of accessibility and inclusivity, as much as possible, given each context. Our group is diverse with respect to ability, race, class, gender, sexual orientation, faith, age, and lived experiences. We hold open spaces, create opportunities, and provide supports towards feelings of safety and emotional comfort so that group members can share and reflect on the experiences and perspectives of one another, with respect and appreciation for our diverse ways of knowing. As unpredictable social contexts (such as the pandemic) shift and change, we support fluid ways of adapting, centering trauma-informed values of consent, relational autonomy, attention to care needs and power relations. These values strongly align with Tronto's and Fisher's (Tronto, 2013) process of caring-with. We view our efforts to counter epistemic violence as a care practice. Attending to access and inclusion in research is a care practice. From a care ethics lens, inclusive research can be understood as care work (Fudge Schormans, 2015).

### Crippling inclusive arts-based research as a necessary care practice during the COVID-19 pandemic

What has been important to the DiStory project, particularly to the disabled co-researchers, is how the work of the project and the ways of working together centre their stories, experiences and knowledge through arts-based methods of expression. They repeatedly tell us not only that they value opportunities to share their stories and knowledge with each other and with non-disabled co-researchers, but that it is through this sharing that they believe change can occur. Upon its completion, the group plans to share knowledge generated in this project with post-secondary students and younger generations of people labelled/with intellectual disabilities through the development of curriculum materials. In the DiStory project, crippling arts-based research methods emerged as a necessary care practice during the COVID-19 pandemic. Crippling research practices to support different ways of knowing challenges the ableist/sanist values, inherent in research that privileges an autonomous normative bodied/minded subject. In the following sections we share tensions, difficult conversations and lessons learned with respect to how we had to change or *pivot* our research practices and how we fought to sustain our group's core values in the context of the COVID-19 pandemic.

#### Research before the pandemic

DiStory had been envisioned as an inclusive, collaborative project. As noted, the intention, from the beginning, was to collectively plan and do the work of the project in and through inclusive workshops. Prior to the pandemic, we were working consistently in the same space – an accessible and comfortable community space with a large room flowing with natural light, large tables and artwork on the walls. It had smaller spaces for small group work, as well as a room that people could use if they needed to be alone or to chat with another group member for support. Food was always included in the workshops, each of which began and ended with check-ins and facilitated exercises (led by varying group members) to attend to people's feelings. Various arts-based methods were used to support different ways of knowing and expressing one's ideas and experiences, including drama-based exercises, music and singing, graphic facilitation, drawing and painting. Identified as useful by DiStory members, these were facilitated by the arts facilitator

and graphic artist group members. In the early workshops, when sharing of stories first began, we knew the stories that would be shared would be difficult to tell, depict, see and hear and so made sure a social worker (not connected to the project) was on-hand for support. We view such considerations as radical acts of care – caring about, caring for, caregiving, care receiving and caring with – in that we collaboratively recognize and attend to the unjust lack of choices, comfort, and social supports that many group members have experienced in their lives, growing up in punitive environments, and still having little choice with respect to their care or surroundings.

Since its inception, the DiStory project has been comprised of several smaller projects aimed at sharing stories and composing teachings in varying ways to support development of text-based and arts-based learning materials about the history of intellectual disability, the past and present lives and realities of people labelled/with intellectual disabilities. This attention to different ways of knowing and doing aligns with values of crippling research methods, disability justice values of recognizing wholeness, inclusive research values of accessibility, and acts of *caring with* that value democratic approaches to knowledge building. Prior to COVID-19, smaller projects included digital storytelling, creating learning materials for post-secondary students (including video and arts materials created by co-researchers labelled/with intellectual disabilities), developing a website where project materials could be accessed, and an arts event – a theatre performance – to share the work and reach out to connect with others. The pandemic however has impacted both our ways of working and our ability to complete some of these projects.

#### *How the COVID-19 pandemic impacted our work together*

To offer some context, DiStory activities have taken place in Toronto, Canada. Our first province-wide lock down began in March of 2020 (Nielsen, 2020) in response to the [World Health Organization's announcement \(2021\)](#) of the COVID-19 pandemic. Both provincial and federal governments instructed citizens to stay home in a collective effort to prevent spreading the virus. Services deemed non-essential were closed. Many university-based research projects were put on hold.

Over the ensuing months, education and non-essential employment and community programming resumed virtually through various video-based technology services, requiring computers, cameras, internet, and computer literacy. Healthcare services, social services, and research initiatives *pivoted* to internet-based video conferencing. Research was again permissible, but only via video conferencing or phone calls – in-person activities were strictly prohibited. While more accessible to some, these shifts laid bare pre-existing digital social inequities across ability, race, gender, class, and age, experienced as social exclusion by marginalized individuals, families and communities who were unable to afford or access digital technology for many reasons (Friedman & Satterthwaite, 2021; Zheng & Walsham, 2021). Consequent to ongoing discrimination in education, and reliance on inadequate levels of disability funding, people labelled/with intellectual disabilities were particularly hard hit – many lacked access to technology and/or the internet due to lack of funds; others who had not received support to learn to use technology in their school years, now lacked access to support staff for such learning (Fudge Schormans et al., 2021).

The impacts of the pandemic were significant among DiStory group members labelled/with disabilities, very few of whom were able to participate in virtual research activities for the reasons cited above. Negotiating communication strategies across group members was a very messy moment for us because we so highly valued our collaborative and interactive ways of working. Several group members labelled/with disabilities live in group home settings where they experienced visitation bans, bans on if they could go out, where they could go and how long they could be in the community. Many had restricted access to support workers and community program staff, leading to extreme isolation, particularly those in independent living arrangements (Fudge

Schormans et al., 2021). No longer able to practice inclusion as we had been doing, it was quite clear that we needed (paraphrasing McRuer and Wilkerson, 2003) to be inventive, think expansively, and do things differently, while still aligning our approach with disability justice and inclusive research values of access and inclusion. Importantly, we had to find a way to maintain contact with disabled group members to offset, at least in part, some of the isolation they were experiencing. We heard from some that staying involved in project work was useful, it gave them something to do, something that they valued. Instead of placing the work on hold, we responded by having research assistants coordinate weekly phone calls with members labelled/with intellectual disabilities and encourage and support existing circuits of communication between group members. These conversations have been difficult because some group members have had access to video-based means of communicating, flexible access to a private space, and some have not. Some group members have expressed a desire to learn how to use the technology, but do not have the equipment and we have been unable to provide this or the in-person support they desire to learn how to use it. Finally, other group members have expressed discomfort with video-based technology, or had privacy concerns and prefer one-on-one conversations on the phone, relying on the research assistants to cross-communicate between group members. As much as we have tried to be inclusive and accessible, not everyone has always agreed, felt included the way they wanted to, or fully understood the positions of others. While messy, we view our efforts to shift prior practices, attempting to maintain DiStory values, as an act of caregiving. This act of caregiving is a response and acknowledgement of care needs connected with the ongoing need to be included, and the need to attend to feelings of fear and isolation brought on by social restrictions. It is also an act of *caring with*, in recognition of the unjust history of isolation, segregation, and inequality experienced by many people labelled/with intellectual disability.

Experiences of such isolation and segregation were new to a few group members, yet were very familiar to others. They differed as well as a function of members' diversity beyond disability. A desire was expressed by group members labelled/with intellectual disabilities to teach non-disabled others about the impacts of the pandemic on their lives. To document these diverse experiences, as a group we decided to compile their stories through telephone conversations between research assistants and group members labelled/with intellectual disabilities in the summer of 2020. In this way we attended to values observed across intersectionality theory, disability justice, inclusive research, and ethics of care. For example, bringing attention to social inequities created and/or exacerbated by pandemic responses, continuing to share power through collaboration and relational interdependence, aims toward collaborative liberation – intentionally sharing these experiences publicly in hopes of garnering support towards action benefitting the interests of this marginalized group. Interview responses are being developed into journal articles and blog posts, collaboratively written by various groupings of project members, to be published or posted on our project website. The collaborative act of creating space for these stories to be shared and disseminated is understood as *caregiving* in response to the need to make marginalized experiences visible. Many of our group members and communities labelled/with intellectual disability have experienced epistemic silencing in the face of digital inequality and social isolation during the pandemic. Working toward the democracy of knowledge building and sharing can be understood as a form of *caring with*, as an act of social justice that counters epistemic silencing.

As vaccines became available in 2021 and numbers of COVID-19 cases decreased, the provincial government granted permission for many places and practices to resume operating as they had been prior to the pandemic, with some regulations in place (i.e., masking, showing proof of vaccination) (Province of Ontario, 2021a). Yet many developmental services that support people labelled/with intellectual disabilities continued to remain closed or run programs virtually, with ongoing visiting restrictions to many residential programs (Developmental Services Ontario, 2021; Province of Ontario, 2021b). Our university

research ethics regulations also continued to restrict in-person meetings. Similarly, our comfortable and accessible space where we used to meet also remains inaccessible. One group member, Kevin John Head, shares his thoughts on the ongoing restrictions:

*It affects everybody. You can't go out. It's awful to stay home. I can't go meet new people, be near people. It's not very nice for me, that's not me you know. I want people. COVID-19 affects me. We're still staying home.*

Another group member, Cindy Scott, echoes Kevin's feelings:

*I wish it was back to normal. It's been great to be able to meet some people. I'm hoping we can get back together. Everybody's wearing masks and I'm getting tired of it. It's hard to breath with a mask. It's hard to see people talking [when they wear masks] because I read lips, because I'm a bit deaf.*

#### *How we shifted our practices while remaining aligned with our values*

As noted, prior to the pandemic, we were planning a collaborative in-person arts-based performance event at an accessible community theatre venue. The event was to launch our website and learning materials to the public, as well as collaborate with other community-based groups that share similar goals, supporting possibilities for collective access and cross-movement solidarity in alignment with disability justice. As the weeks rolled into months and years, it became apparent this would not be possible; we would need to "imagine otherwise" (Eales & Peers, 2021, p.164). Partnering with a local community arts-based organization, group members who comprised the arts event small group generated some options for shifting from an in-person arts-based project to a virtual format, that would be widely accessible via posting on our website. (Thinking through ways to use a virtual format for cross-disability collaboration is ongoing.) Through phone conversations with all project members, we decided in the summer of 2021 to embark on an arts-based project focusing on previous care experiences and reimagined forms of care for future generations. Co-researchers labelled/with intellectual disabilities collaborated in planning to create individual visual art works which would be followed by audio recorded conversations between each disabled co-researcher and the academic research coordinator about the art images and experiences. As a care practice, this collaboration and relational interaction was designed with the intention to support values of accessibility, democracy, relationality, and power sharing.

Logistically, this initiative entailed extensive telephone communication between Erin Kuri and 13 group members<sup>6</sup> labelled/with intellectual disabilities to generate ideas, gather documented consent, and make a list of visual art materials each group member preferred to work with. Academic and community-based non-labelled group members purchased art materials and created art kits that were delivered by mail. Included in the mailing were plain language guidelines for the art making. Erin communicated by phone with the group members to ensure they received their art kits, reviewed the guidelines verbally, ensured in-person supports were available to them if necessary, and answered any questions they had before creating their art images. Group members then engaged in the visual art-making in their own space and time. This gave them the time to consider what experiences they wanted to depict and to work on their art at their own pace. The process and conversations were difficult at times due to length of time across conversations, mailing of materials and scheduling of interviews. Conversations needed to be repeated at times and plans needed to be renegotiated if group members changed their minds about materials or how they wanted to make their art. Combined, these considerations and

attention to access and inclusion reflect both crippling practice and acts of *caregiving, caring about, for, and with*, in alignment with disability justice and inclusive research principles of access and interdependence. A downside to the use of phone calls was that as an arts-based researcher (with training as a trauma-informed art therapist), Erin was unable to witness the creative process which can offer a great deal of knowledge in connection to in-the-moment context surrounding the creation of the images. She was also unable to assess the need for in-the-moment emotional support if the art making triggered difficult feelings in connection with the subject matter. *Caring about, care-giving, caring for and with* were evident in her attempts to mitigate these risks by ensuring everyone had access to in-person support, if needed. Offering to be available by phone during or after artmaking (an offer taken up by some group members) was an enactment of *care receiving, that is, ongoing assessment of care needs and if the needs were met*.

Two group members who wished to participate in the arts-based project expressed that they were unable to carry out the visual art making on their own. Prior to the pandemic, another group member (with a vision impairment) chose to engage in visual art-making by working with a research assistant who could draw images or cut out magazine images for him, giving us a precedent for how to shift our practices. For these two co-researchers, Erin drew pictures over the phone on their behalf, based on what they told her to draw about their experiences, and how they wanted the image to appear. As a care practice that counters historical exclusions from knowledge production, positive aspects of this approach were that these group members could be included in the project and their knowledge would contribute to the group's collective knowledge about the topic. A major challenge was the risk that the academic group member might misunderstand or misrepresent the contributor's intentions, and thus inadvertently impose upon their work. To mitigate this risk, she provided as much verbal feedback as possible as to how the image appeared while drawing, checking continuously if this was the image they pictured in their minds. Another mitigating step will be to mail each group member a coloured photocopy of their image to verify its accuracy or gather feedback for required changes. Aligning with principles of crippling, inclusion, and care ethics, access was a major consideration in each step of our project design. Before and during COVID-19, we have incorporated a range of options for everyone participating in the project. Our purpose in using art materials is not to teach art-making skills, but to facilitate access, recognizing that group members hold different levels of skill and comfort with art, and communicate and make art in different ways. Collaboratively adapting the work in these ways, disrupts ableist ways of knowing and doing in research.

After the art pieces had been completed, with their documented permission Erin engaged with each group member in verbal, audio-recorded conversations over the phone. Group members described the art image they had created and what it meant to them. Erin engaged in a relational conversation with each group member, taking a non-judgemental stance of curiosity, openness, appreciation and validation. Communicating this attitude when working together can support the creation of safer space where different ways of being, knowing, and doing can be possible. Verbal communication of this attitude over the phone can happen directly through stating how there is no right or wrong way to make art or share, and indirectly through silence and patience that creates space for the person to reflect or respond, or through verbal cues that suggest one is interested, curious, and attending to what the other is saying. Erin offered prompts when appropriate, to elicit deeper understanding about various aspects of the images and the context surrounding them, in connection with the focus of the project. As noted, it was difficult, and in some ways impossible, to keenly identify the need for care or sensitivity when unable to read group members' facial expressions or body language. She felt her relational responses would have been more attuned were we sharing physical space where we could read and emotionally sense one another through non-verbal ways of communicating. After the phone

<sup>6</sup> One of the 14 co-researchers labelled/with intellectual disabilities chose not to participate in this activity, nor were they interested in an alternative at this time.



conversations, audio recordings were transcribed, and Erin arranged for the group members to mail their art images in postage-paid envelopes to Ann. In this project activity (as in other project activities) group members labelled/with intellectual disabilities received honorariums as a sign of respect, in appreciation of their time, and in recognition that many are financially dependent on government financial assistance to live (and thus made to live in poverty), therefore, these honorariums were helpful for them. It also acknowledges that research assistants and community partners are paid for their work on the project and that research work is an expectation of academic researchers and included in their employment contract.

Erin Kuri and Ann Fudge Schormans are currently matching the transcribed interviews with the visual images themselves for thematic analysis. When completed these findings will be brought back to the group for verification and feedback – using phone calls if necessary or via in-person workshops if allowed. The following stages of the project – determining how to present the images virtually, in combination with other forms of arts-based dissemination methods – will all be collectively guided by the group and supported by the community-based arts organization working with us.

Overall, this process of creating art and engaging with visual arts-based conversations was far different than if conducted in-person rather than over the phone. However, given the social distancing restrictions surrounding the unusual and complex context of a pandemic, pivoting our practices as we did – while arguably less collective – sustained our values of social inclusion, embodied and sensory ways of knowing, accessibility, and collaboration. Linking it to care, group members expressed appreciation for the extended time to create their visual art, for having more one-on-one attention and time to describe what their images meant to them. Such a degree of time and individualized attention might not have been possible in a group workshop setting for so many people creating visual art and sharing the details of their images and experiences in as cohesive a manner.

### Connecting values with practice

Through the practice example we shared of DiStory, we demonstrate how complex contexts and considerations can collide in ways that move research teams into places of tension, but can also be generative spaces for possibility. By engaging with guiding principles of inclusive research, intersectionality, disability justice, and ethics of care, we aimed to sustain our values as a collaborative research group. We also explored instances when we were less able to work as a collective, or to determine or meet the needs of all group members in the ways we had planned prior to COVID-19. In this section, we return to the guiding principles we discussed earlier in the article, exploring where practice and theory came together for group members through arts-based interviews and the ways we strove to build knowledge together.

### Relationality and power

Themes relating to power, equality, interdependence and leadership have been significant in our work as a group. Amidst barriers to social contact during the pandemic, our group has remained committed to connection with one another, albeit in different forms, to a different degree, and with far less direct connection between small and large groups of people. This web of care nonetheless facilitates and sustains the rights of labelled group members to continue sharing decision making power and space to contribute ideas. Arts-based telephone interviews were the method chosen by our group, embracing the diversity of their experience and knowledge to be expressed in unique and individualized ways. Group members labelled/with intellectual disabilities maintained control over the subject matter and the methods used, and will collaborate as to how and with whom the art work will be shared, thus ensuring that their inclusion and interests are prioritized.

### Democracy, accessibility, and inclusivity

We recognize in our work that when everyone is involved in decision making, we may not always all agree. Where possible, we aim to create space for choice and differences in how people engage with large and small project activities. This was demonstrated in our example, where group members were given their choice of materials to work with. If they felt that art making was not possible for them, we explored alternative sharing options that were meaningful for them given our social constraints. We endeavored to make research materials accessible and as a group we plan for ways to publicly share the knowledge that comes from this project in multiple accessible formats for the broader community. Pandemic safety regulations posed a significant challenge to our collaborative inclusive project. Changing up our practices given these constantly shifting complex contexts and diverse needs of group members labelled/with intellectual disabilities, we found ways to support their meaningful inclusion, as well as inclusivity of diverse ways of knowing and being in our project, which our group members have expressed go beyond the project with respect to the meaning these actions have in their lives as a whole.

### Complexity, crippling and epistemic justice

At the heart of intersectionality theory is the notion of complexity. We understand that complex aspects of identity are forged amidst oppressive social constructions, entwined with material lived experience, interconnected relational webs of power, and new ways of becoming together. In the DiStory project we aim to embrace and explore the complex and embodied ways we experience the worlds around us, to explore and share marginalized knowledge with dominant groups who have historically oppressed people labelled/with intellectual disability. One way of honouring the many forms of complexity in relation with our research group is how we make space to explore tensions. Crippling our practices, we strive to embrace fluidity, to be open to shifts and changes in how we do things to ensure everyone has space to be heard, to influence one another and to contribute to the collective knowledge shared by the group. Epistemic justice is not only about having one's voice heard, it is about exercising one's right to join the broader conversations that centre social justice and the interests of those most marginalized. We view these goals and practices to be aligned with the spirit and call for Disability Justice.

### Conclusion

In this article, we discussed the practice of inclusive research as a form of care work that seeks to counter epistemic violence endured by people labelled/with intellectual disability. We explored and identified connections across core values between inclusive research, intersectionality theory, Disability Justice, and ethics of care. We then shared an example of how such values and approaches were put into action during a time of global trauma and uncertainty, challenging us to pivot our approaches through visual arts-based research while sustaining the values we cherish – and that sustain us – as a group. We discussed challenges that emerged in our process of shifting the way we practiced, what was lost as well as unanticipated benefits of shifting in these ways. We appreciate that the process of shifting, pivoting or crippling research practices is a fluid and context specific practice, acknowledging also that each project and context will be unique, therefore we do not offer our experiences as a map or set of guidelines to follow. Instead, we encourage creative arts-based practitioners and researchers to consider how they integrate values of social justice and critical theoretical concepts into the choices they make, how they reflexively interrogate these decisions, and how they assess and shift practices along the way to sustain their values in collaboration with the people they engage in knowledge building with. Our DiStory project is ongoing at the time of writing this article. We continue to collaborate toward our goals in yet

another wave of the COVID-19 pandemic. We accept that the project will take longer to complete, that it will take the time it needs to take in order to adhere to values of epistemic justice, inclusive research, and ethics of care.

## Declarations of interest

None.

## funding

This project has been funded by the Strategic Program Investment/ Investing in Justice Fund, Ontario Ministry of Community and Social Services Program Policy Implementation Branch – Litigation Unit.

## Acknowledgements

We wish to thank the peer reviewers and editors who helped to strengthen our manuscript. Most importantly, we wish to thank all members of the DiStory group for their participation and insights into our ongoing collaborative work together. As a community we stand for disability justice, (re)membering past wrongs while shaping a more caring and inclusive society for future generations.

## References

- Bain, A. L., & Payne, W. J. (2016). Queer de-participation: Reframing the co-production of scholarly knowledge. *Qualitative Research*, 16, 330–340. <https://doi.org/10.1177/1468794115619002>
- Berne, P., with the support of Levins Morales, A., Langstaff, D., & on behalf of Sins Invalid. (2018). Ten principles of disability justice. *WSQ: Women's Studies Quarterly*, 46(1–2), 227–230. <https://doi.org/10.1353/wsq.2018.0003>
- Bigby, C., Frawley, P., & Ramcharan, P. (2014aaa). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27, 3–12. <https://doi.org/10.1111/jar.12083>
- Bigby, C., Frawley, P., & Ramcharan, P. (2014bbb). A collaborative group method of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 27, 54–64. <https://doi.org/10.1111/jar.12082>
- Clare, E. (2017). *Brilliant imperfection: Grappling with cure*. Duke.
- Cooper, B. (2016). Intersectionality. In L. Dirsch, & M. Hawkesworth (Eds.), *The Oxford handbook of feminist theory* (pp. 385–406). Oxford University Press.
- Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antiracism doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*, 140, 139–176.
- Developmental Services Ontario. (2021, July 20). Developmental Services Ontario COVID-19 Update. Developmental Services Ontario. (<https://www.dsontario.ca/agencies/dso-toronto>).
- Eales, L., & Peers, D. (2021). Care haunts, hurts, heals: The promiscuous poetics of queer crip Mad care. *Journal of Lesbian Studies*, 25(3), 163–181. <https://doi.org/10.1080/10894160.2020.1778849>
- Fricke, A. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford.
- Friedman, M., & Satterthwaite, E. (2021). Same storm, different boats: Some thoughts on gender, race, and class in the time of COVID-19. In A. O'Reilly, & F. Joy Green (Eds.), *Mothers, mothering, and COVID-19: Dispatches from a pandemic* (pp. 53–64). Demeter.
- Fudge Schormans, A. (2015). People with intellectual disabilities (visually) re-imagine care. In M. Barnes, N. Ward, L. Ward, & T. Brannely (Eds.), *Renewing Care: Critical International Perspectives on the Ethics of Care* (pp. 179–193). Policy Press.
- Fudge Schormans, A., Allan, H., Allen, O., Austin, C., Pierre, R., Elbard, K., ... Rowley, S. (2019). Research as Activism? Perspectives of People Labelled with Intellectual and Developmental Disabilities in Inclusive Research and Co-production of Knowledge. In M. Berghs, T. Chataika, Y. El-Lahib, & K. Dube (Eds.), *Routledge Handbook of Disability Activism* (pp. 354–368). Routledge.
- Fudge Schormans, A., & Chambon, A. (2012). The re-working of spatial attribution: People with intellectual disabilities and the micropolitics of dissensus. *Review of Education, Pedagogy, & Cultural Studies*, 34(3–4), 123–135. <https://doi.org/10.1080/10714413.2012.687241>
- Fudge Schormans, A., & Chambon, A. (2014). "Please don't let me be like this!" Unwounding photographic representations by persons with intellectual disability. In S. Brophy, & J. Hladik (Eds.), *Embodied Politics in Visual Autobiography* (pp. 171–188). University of Toronto Press.
- Fudge Schormans, A., Hutton, S., Blake, M., Earle, K., & Head, K. J. (2021). Social Isolation Continued: Covid-19 Shines a Light on what Self-advocates Know Too Well. *Qualitative Social Work Special Issue: Research and Practice Special Issue: Reflections on a Pandemic: Disruptions, Distractions, and Discoveries*, 20(1–2), 83–89. <https://doi.org/10.1177/1473325020981755>
- Garland-Thomson, R. (2005). Disability & representation. *PMLA*, 120(2), 522–527. Retrieved June 2, 2021 (<http://www.jstor.org/stable/25486178>).
- Hill Collins, P., & Bilge, S. (2016). Intersectionality. *Polity*.
- Ignagni, E., & Fudge Schormans, A. (2016). Re-imagining parenting possibilities: Towards intimate justice. *Studies in Social Justice, Special Issue on Consuming Intimacies: Bodies, Labour, Care, and Social Justice*, 238–260. <https://doi.org/10.26522/ssj.v10i2.1361>
- Kafer, A. (2013). *Feminist queer crip*. Indiana Press.
- Kaplan, F. (2002). Editorial. Cross-cultural art therapy: A now and future therapy. *Art Therapy: Journal of the American Art Therapy Association*, 19(4), 138. <https://doi.org/10.1080/07421656.2002.10129679>
- Kröger, T. (2009). 'Care research and disability studies: Nothing in common?'. *Critical Social Policy*, 29(3), 398–420. <https://doi.org/10.1177/0261018309105177>
- Leavy, P., & Harris, A. (2019). *Contemporary feminist research from theory to practice*. Guildford Press.
- Lewis, V. A. (2015). Crip. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for disability studies* (pp. 46–48). New York University Press.
- Lister, S., Tanguay, D., Snow, S., & D'Amico, M. (2009). Development of a creative arts therapies center for people with developmental disabilities. *Art Therapy: Journal of the American Art Therapy Association*, 26(1), 34–37. <https://doi.org/10.1080/07421656.2009.10129316>
- Logeswaran, S., Hollett, M., Zala, S., Richardson, L., & Scior, K. (2019). How do people with intellectual disabilities construct their social identity? A review. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 533–542.
- McClelland, A., Flicker, S., Nepveux, D., Nixon, S., Vo, T., Wilson, C., ... Proudfoot, D. (2012). Seeking safer sexual spaces: Queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction. *Journal of Homosexuality*, 59(6), 808–819. <https://doi.org/10.1080/00918369.2012.694760>
- McRuer, R., & Wilkerson, A. L. (2003). Introduction. *GLQ: A Journal of Lesbian and Gay Studies*, 9(1–2), 1–23. <https://doi.org/10.1215/10642684-9-1-2-1>
- Miller, S. M., Ludwick, J., & Colucy Krcmar, C. (2020). Professional considerations for art therapists supporting the work of people with intellectual disabilities. *Art Therapy: Journal of the American Art Therapy Association*, 37(2), 83–87. <https://doi.org/10.1080/07421656.2020.1757376>
- Nielsen, K. (2020, 24). A timeline of COVID-19 in Ontario. *Global News*. (<https://globalnews.ca/news/6859636/ontario-coronavirus-timeline/>).
- Nielsen, K. E. (2012). *A disability history of the United States*. Beacon Press.
- Piepna-Samarasinha, L. L. (2018). *Care work: Dreaming disability justice*. Arsenal Pulp Press.
- Price, M., & Kerschbaum, S. L. (2016). Stories of methodology: Interviewing sideways, crooked and crip. *Canadian Journal of Disability Studies*, 5(3), 18–56. <https://doi.org/10.15353/cjds.v5i3.295>
- Province of Ontario. (2021a). A plan to safely re-open Ontario and manage COVID-19 for the long term. *Province of Ontario*. (<https://covid-19.ontario.ca/plan-safely-reopen-ontario-and-manage-covid-19-long-term#october-25-2021>).
- Province of Ontario. (2021b, May 18b). Developmental Services in Ontario. Province of Ontario. <https://www.mcsc.gov.on.ca/en/MCSC/programs/developmental/index.aspx>.
- Runswick-Cole, K., & Goodley, D. (2015). Disability, austerity and cruel optimism in big society: Resistance and "the disability commons". *Canadian Journal of Disability Studies*, 4(2), 162–186. <https://doi.org/10.15353/cjds.v4i2.213>
- Sandahl, C. (2003). Queering the crip or crippling the queer? Intersections of queer and crip identities in solo autobiographical performance. *GLQ: A Journal of Lesbian and Gay Studies*, 9(1–2), 25–56. <https://doi.org/10.1215/10642684-9-1-2-25>
- Schrade, C., Tronsky, L., & Kaiser, D. H. (2011). Physiological effects of mandala making in adults with intellectual disability. *The Arts in Psychotherapy*, 38(2), 109–113. <https://doi.org/10.1016/j.aip.2011.01.002>
- Talwar, S. K. (2019). Identity matters: Questioning trauma and violence through art, performance, and social practice. In S. K. Talwar (Ed.), *Art therapy for social justice: Radical intersections* (pp. 38–65). Routledge.
- Titchkosky, T. (2001). Disability: A rose by any other name? "People-First" language in Canadian society. *Canadian Review of Sociology/Revue canadienne Déléfôt Sociologie*, 38(2), 125–140.
- Trent, J. W., Jr. (1994). *Inventing the feeble mind: A history of mental retardation in the United States*. University of California Press.
- Tronto, J. C. (2013). *Caring democracy: Markets, equality, and justice*. New York University Press.
- Trzaska, J. D. (2012). The use of a group mural project to increase self-esteem in high-functioning, cognitively disabled adults. *The Arts in Psychotherapy*, 39(5), 436–442. <https://doi.org/10.1016/j.aip.2012.06.003>
- Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability and Society*, 16(2), 187–205. <https://doi.org/10.1080/09687590120035807>
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley.
- World Health Organization. (2021). *Timeline: WHO's COVID-19 response*. World Health Organization: Coronavirus disease (Covid-19). (<https://www.who.int/emergencies/diseases/novel-coronavirus-019/interactive-timeline>).
- Yi, C. (2010). From imperfect to I am perfect: Reclaiming the disabled body through making body adornments in art therapy. In C. H. Moon (Ed.), *Materials and media in art therapy: Critical understandings of diverse artistic vocabularies* (pp. 103–118). Routledge.
- Yi, C. (2019). Res(crip)ting art therapy: Disability culture as a social justice intervention. In S. K. Talwar (Ed.), *Art therapy for social justice: Radical intersections* (pp. 161–177). Routledge.
- Zheng, Y., & Walsham, G. (2021). Inequality of what? An intersectional approach to digital inequality under Covid-19. *Information and Organization*, 31, 1–6. <https://doi.org/10.1016/j.infoandorg.2021.100341>