



Essay

# Disability Theatre as Critical Participatory Action Research: Lessons for Inclusive Research

Rachelle D. Hole<sup>1,2,\*</sup> and Leyton Schnellert<sup>1,3</sup>

<sup>1</sup> Canadian Institute for Inclusion and Citizenship, The University of British Columbia, Vancouver, BC V6T 1Z4, Canada; leyton.schnellert@ubc.ca

<sup>2</sup> School of Social Work, Faculty of Health and Social Development, The University of British Columbia, Kelowna, BC V1V 1V7, Canada

<sup>3</sup> Department of Curriculum and Pedagogy, Faculty of Education, The University of British Columbia, Vancouver, BC V6T 1Z4, Canada

\* Correspondence: rachelle.hole@ubc.ca

**Abstract:** Informed by critical disability studies and disability justice, this article describes the reflections of two university researchers co-researching with self-advocates (individuals with intellectual disability), theatre artists, researchers, and a community living society to create social justice disability theatre as critical participatory research (CPAR), demonstrating how disability theatre can contribute to and advance inclusive research practice. Disability justice-informed theatre as CPAR has direct relevance to people with intellectual disabilities; offers a platform where self-advocates' diverse ways to communicate and be in the world are honoured and taken up as resources to the research and community; and can generate mentorship opportunities for self-advocates to learn, practice, and develop research skills. Significances include showing how the theatre creation process (devising, developing, and refining scenes) is research in itself and how tensions are recognized as sites of possibility. Future research should explore how increasing pathways to communication, co-creation of KT strategies, and protocols for power sharing and problem solving within disability theatre as CPAR impact the roles, outcomes, and experiences of disabled and non-disabled researchers and audience members.

**Keywords:** inclusive research; disability theatre; devised theatre; intellectual disability; critical participatory action research



**Citation:** Hole, Rachelle D., and Leyton Schnellert. 2024. Disability Theatre as Critical Participatory Action Research: Lessons for Inclusive Research. *Social Sciences* 13: 116. <https://doi.org/10.3390/socsci13020116>

Academic Editor: Patricia O'Brien

Received: 1 December 2023

Revised: 12 January 2024

Accepted: 8 February 2024

Published: 13 February 2024



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## 1. Introduction

Prompted by the independent living movement, the people's first movement, and solidified by the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), there is growing recognition of the importance and the rights of persons with disabilities to be included as active agents in research (e.g., Nind 2017; Nind and Vinha 2014; Walmsley and Johnson 2003). In fact, since the 1990s, scholars involved in disability research have argued for research informed by an emancipatory paradigm (e.g., Barnes and Mercer 1997; Oliver 1992). This is in response to research that was performed "on", "to", or "about" disabled people without them (O'Brien 2022). Since these early days of emancipatory research, researchers in intellectual disability research committed to working with self-advocates with lived experience (e.g., Nind 2014, 2017; Walmsley and Johnson 2003) have been theorizing, calling for, and advancing principles of inclusive research. Walmsley and Johnson (2003, p. 9) explained that inclusive research is "research in which people with learning disabilities [intellectual disabilities] are active participants, not only as subjects but as initiators, doers, writers, and disseminators of research". Nind extends this understanding rooted in participatory and emancipatory research to include "research with multiple labels that essentially 'reflect[s] a turn towards the democratization of the research process' (Nind 2014, p. 1)" (Nind 2017, p. 279). But this is easier proposed than enacted.

“The issues of what makes inclusive research, how it is done and what its implications are, are contentious for all those involved in it” (Walmsley and Johnson 2003, p. 11).

To guide researchers, Walmsley and Johnson (2003) outlined five principles of inclusive research. These principles are as follows: (a) “The research problem must be one that is owned (not necessarily initiated) by disabled people”; (b) “It should further the interests of disabled people; non-disabled researchers should be on the side of people with [intellectual disabilities]”; (c) “It should be collaborative—people with [intellectual disabilities] should be involved in the process of doing the research”; (d) “People with [intellectual disabilities] should be able to exert some control over process and outcomes”; and (e) “The research question, process and reports must be accessible to people with [intellectual disabilities]” (Walmsley and Johnson 2003, p. 64).

In this article, we offer our experience with disability and devised theatre as critical participatory action research (CPAR) to describe an example of enacting inclusive research where self-advocates, theatre artists, researchers, and a community living society collaborated to create a social justice disability theatre project titled, “*We Deserve to Work!*” Taking up a disability justice lens, we use the term self-advocates to refer to individuals with intellectual disabilities, “a term that positions individuals with [intellectual disabilities] as self-determining and acting with agency” (Schnellert et al. 2022). The purpose of this reflexive narrative is to demonstrate how disability theatre CPAR can contribute to and advance inclusive research practice.

In the following sections, we share our theoretical commitments to critical disability studies and disability justice and their relationship to disability theatre. Next, in Section 2, we set the stage for the paper by introducing our collaborative theatre projects. In Section 3, we describe how we enacted an inclusive CPAR theatre project by examining inclusion across three areas: setting the question(s) and co-constructing research methods, conducting the research, and knowledge translation. Finally, we discuss how our collaboration in a CPAR disability theatre project facilitated principles of inclusive research and present recommendations from our learnings.

### 1.1. Sensitizing Lenses

Critical disability studies (CDS) and disability justice inform our work. Rooted in traditional disability studies, CDS integrate new and transformative agendas and theories such as postcolonial (e.g., Sherry 2007), feminist (e.g., Garland-Thomson 2005), and queer and crip (e.g., Chen et al. 2023; McRuer 2006) theories (Goodley et al. 2019). This tapestry of “epistemological perspectives and ontological desires” creates a rich bricolage (Kincheloe 2001) of theorizations of what disability is and what it can do (Goodley et al. 2019, p. 976).

Central to CDS is the understanding that “disability is a political and cultural identity” (Dolmage 2017, p. 10). Rather than viewing disability as a deficit or defect needing to be cured or fixed, disability is understood as a valued part of human diversity, a social/political category that “serves and functions as a basis for political activism” (Schnellert et al. 2023, p. 296). In fact, “CDS informed by disability justice is a movement that challenges ableist normativity and privilege and is committed to ‘revolutionary and accountable praxis to incite radical justice’ (Erevelles 2014, p. 2)” (Schnellert et al. 2023, p. 4690). Given this, CDS researchers committed to the principles of disability justice (Sins Invalid 2019) are implored to critically think about how they enact and operationalize research.

Disability justice, a sociopolitical activist framework, centres the knowledge and wisdom of those most impacted by ableism and its complex entanglement with other forms of oppression—e.g., racism, heterosexism, and colonialism (Sins Invalid 2019). Disability justice in research thus requires engagement in activist practices to centre justice and reframe access, ethics, and equity (Keifer-Boyd et al. 2018), thus aligning with principles and practices of inclusive research described above (e.g., Walmsley and Johnson 2003). CDS and disability justice researchers, who work with individuals with intellectual disabilities, look to forms of inclusive research as a means to include individuals with intellectual disabilities in research in meaningful ways and to effect change that is central to self-

advocates' concerns and desires. Disability justice-based methodologies offer a valuable framework to enact inclusive research principles.

### 1.2. Disability Theatre

Disability theatre strives to challenge societal norms through productions related to social justice. Johnston (2016, p. 15) writes that disability theatre is “broadly connected to impulses for social justice in the face of ableist ideologies and practices as well as a profound recognition of disabled lives and experiences as inherently valuable”. Devised approaches to theatre such as Boal’s Theatre of the Oppressed (Boal 2002) intersect well with disability theatre as both offer disabled actors opportunities to create characters, scenes, and messages that can directly address stereotypes and stigma. Disabled actors defining the issues, messages, and perimeter of disability theatre projects is an enactment of disability justice (Schnellert et al. 2023). Bringing together disability justice, disability theatre, devised theatre, “press[es] the boundaries of aesthetic convention on the other. [D]isability theatre is thus both activist and artistic in orientation” (Johnston 2016, p. 15).

Disability theatre is not only political seeking to address ableism, but also aesthetically challenging. This aesthetic sensibility aligns well with CDS as disability theatre recognizes that we experience the world through the senses—and “the body acts as conceptual glue. . . in broadly the same way disability aesthetics. . . changes the role of art and the artist” (Conroy 2009, p. 11). Disability aesthetics change art disrupting normalized concepts of identity and non-disabled privilege and offer access for those with diverse modes of knowing, being, and doing (Decottignies 2016). In a similar way to which disability aesthetics changes art, disability theater challenges and can expand theatre and research processes (Schnellert et al. 2022).

Disability theatre informed by disability justice requires us to change as artists and researchers when we engage in ethical theater-making and knowledge-sharing processes. Disability justice principles—e.g., centring the voices of those who are the most impacted, recognizing the wholeness of each person, interdependence, collective access as an on-going flexible and creative process, and collective liberation where no body/mind is left behind—are clarion calls for action that centres the collective throughout the theatre research processes. Assumptions about how we communicate, how we live in the world, and how we make sense of the world can be transformed through research-based disability justice theatre (Schnellert et al. 2023).

## 2. Setting the Stage: “Romance, Relationships, and Rights” and “We Deserve to Work!”

In 2017, we undertook a participatory theatre research project regarding the sexual agency of individuals with intellectual disabilities (Schnellert et al. 2022, 2023). The development of the disability theatre project, “*Romance, Relationships, and Rights (RRR)*”, was initiated when the executive director of a community living agency approached researchers at the University of British Columbia’s Canadian Institute for Inclusion and Citizenship (CIIC) to learn about how their agency can better support self-advocates’ sexual citizenship. To disrupt sexual ableism, and to centre the lived experience and perspective of individuals with intellectual disabilities, we turned to disability and devised theatre.

Disability justice connects disability and devised theatre through commitments to “transformative accountable praxis” (Erevelles 2014, para. 26). Our research highlighted the potential and contributions of disability and devised theatre within CPAR and also revealed tensions of power, representation, and voices (Schnellert et al. 2022, 2023). We took what we learned from this first collaborative disability theatre PAR study to plan and enact our next disability theatre project, “*We Deserve to Work (WDTW)*”, a play on employment.

Self-advocates from the Community Living Society (CLS), researchers from the CIIC, and professional theatre artists undertook the creation and production of social-justice-oriented disability theatre—WDTW—as critical participatory action research (CPAR). CPAR aligns well with disability justice, disability theatre, and inclusive research. CPAR “is a framework for engaging research with communities interested in documenting, challenging,

and transforming conditions of social injustice” (Fine and Torre 2021, p. 3). CPAR places participants at the centre of the research not only to illuminate their voices as they strive to make social change but also to encourage researchers to work alongside participants throughout the process. CPAR is “rooted in the activist call ‘No research on us, without us’” (Fine and Torre 2021, p. 3).

### 3. The Praxis of Inclusive Research as Disability Theatre

As discussed above, inclusive research informed by disability justice necessarily requires researchers to reflect on how they enact inclusive practices and what they learn from the strengths and challenges of their process to inform future work. We have previously written about findings from disability theatre CPAR projects (Hole et al. 2022; Schnellert et al. 2022, 2023; Tidey et al. 2023). In this essay, we describe how we executed an inclusive CPAR theatre project with respect to three areas: setting the question(s) and co-constructing research methods, conducting the research, and knowledge translation with the aim to contribute insights for inclusive research via disability theatre.

#### 3.1. Praxis Initiation: Setting the Question(s) and Co-Constructing the Research Methods

As researchers from the CIIC, we had collaborated with the CLS in a disability theatre project related to self-advocates’ rights to intimate relationships. The self-advocate co-creators/actors were eager to develop another project, and the CLS agreed to support the development of another research funding application. To develop a focus for our next research-based theatre production, we held two sessions in a gallery and used applied theatre devising techniques to identify possible topics and questions for inquiry.

On two Sunday afternoons, we held devising sessions. We started together as one group where the fifteen co-creators from the RRR production shared what they liked about the previous production and why they thought we should have a second production. Using various communication techniques, all co-creators indicated how much they enjoyed the positive feedback they received about the first production, and many shared how proud they were to shine a light on an issue they cared about (Schnellert et al. 2022). They also highlighted how fulfilling it was to create scenes that communicated their messages. Then, we moved into two groups to generate possible topics for our next production. Through the use of tableaux and co-creating scenarios, each group arrived at two possible topics and presented them to the other group. As reported by one self-advocate, “We were coming up with what ideas we do for the next play and we settled on work [as our next play’s focus]”.

Researchers took notes on chart paper as self-advocates shared why employment can be an important and necessary topic for others to learn about. Group members shared a variety of reasons drawing from their lived experience: some of the self-advocates in the group had jobs but wanted new jobs or to advance in their jobs; others were not currently employed; and still others had no previous paid work experience. Across all participants, they felt that creating an employment-focused play could make a difference for themselves and others in the disability community, their families, and those who support them. One self-advocate shared, “[A lot of people think that people with disabilities can’t work]. . .and we’re trying to show them that that’s not how it is. That there is work we can do. That we can hold down jobs; that we’re basically just like everybody else”. Another stated, “I want employers to hire people who are [disabled]”.

At our third meeting, we gathered at the CLS to collectively develop the research proposal. In our previous production, the research proposal was written by researchers and the CEO of the CLS, but this time out, self-advocates were eager to be part of the entire process from identifying the topic for our next production to generating aspects of the research proposal. Revisiting our chart paper notes from the devising sessions, the self-advocate co-creators shared their confirmed commitment to a focus on employment. Using notes taken at the development sessions, they also shared and reflected on the previous production and theatre creation processes to decide what to keep and change. At this meeting, the self-advocates took part in developing a timeline for the production, building

a research phase into the development of the play, activities to develop scenes (theatre devising processes), their desire to travel the show to other venues, and video-recording the play so that it can be shared beyond live performances. In addition to the self-advocates, the leaders of the Massey Theatre, CLS, and CIIC as well as theatre artists participated in this collective proposal development meeting.

### 3.2. Praxis Enactment: Conducting the Research

“To prepare for the play we had to do data research” (SA Co-Creator). As an initial phase of the WDTW project, we conducted focus groups with employers, employment specialists (coaches), and self-advocate employees as part of the theatre development process. The self-advocate co-creators were co-researchers in this process: “talking to employers, job coaches, and self-advocates, that’s how we got our research” (SA Co-Creator). Similar to [Seale et al. \(2015\)](#), self-advocates in this project generated interview questions; chose roles for the research process (interviewer, note taker, and time keeper); practiced these roles; and conducted the focus group interviews on Zoom. Following transcription, the self-advocates collectively looked at the data in small groups and identified themes. They took cut-up sentence strips from the interviews and grouped them together in categories. Then, the co-creators, facilitated by theatre co-directors (one of whom is a CIIC researcher), used the findings to devise thematic messages from the categories. With the messages as references, the self-advocates created tableaux, developed them into mini-scenes and ultimately created two Acts within the WDTW production. These Acts were bracketed with an Introduction, Interlude, and Closing entirely composed of direct quotes from the research. In these ways, the self-advocate co-creators were involved in doing the research.

WDTW was produced in the Massey Theatre with one matinee performance and two evening performances, and then the play travelled to two conferences with large audiences. Audience feedback from performances was iteratively used to adapt and travel the show. The feedback was transcribed into charts and in two groups the self-advocates read and discussed the feedback, once again identifying themes. They used the data to clarify and emphasize certain line readings and messages in successive performances. Debriefing after the theatre performances and travelling shows, the self-advocate co-creators brainstormed directions for the next research proposal (e.g., housing).

### 3.3. Practice Enactment: Knowledge Translation

The theatre format allowed for knowledge translation (KT) that communicated themes and messages in multi-modal ways with embedded access points for audiences. The self-advocate co-creators were not only co-researchers in the more traditional focus groups in Phase One (through interviewing employers, job coaches, and employed SAs), but they were also active in developing and enacting KT strategies.

A staging of the draft performance was mounted at the Inclusion BC Annual Conference where the co-creators and production team received feedback on the draft scenes. They were able to ascertain if and how the themes from the interviews and data analysis were being translated to an audience composed of self-advocates and caregivers. Feedback forms were collected, and ideas were incorporated into the ongoing development process. The project spanned three years from initial planning to developing research skills and conducting focus groups to “play building” to producing and performing WDTW. Each year, three self-advocates from the production sat on the steering committee along with the CIIC, CLS, and Massey Theatre representatives. KT strategies were generated here, and the self-advocate representatives acted as conduits between the co-creators and actors in the theatre company and the steering committee and their organizations. In the first year of the project, the three self-advocate Steering Committee members presented with three CIIC researchers at a national conference for theatre researchers. With the three researchers, they brainstormed an outline for the presentation and who would present and/or co-present each item. One self-advocate described the process of using devised theatre to decide on the focus and timeline for WDTW; another explained how questions were generated for focus

groups and how the group practiced conducting the focus groups; and a third member (who was video-taped ahead of time as he could not attend the conference) spoke about theatre as a medium to communicate disability justice messages. These self-advocates were translating and mobilizing methodological knowledge for an audience of theatre researchers.

Our central WDTW KT strategy was the theatre performances (and video-recording of the performance). Self-advocates played a central role in all aspects of this KT approach. One self-advocate explained, “We had the final say; the script, the lighting, the costumes, even the music selection with the playlists”. The self-advocates in this project were part of creating, adapting, reflecting on, and revising methods. In reference to refining the themes and messages in the play, one individual noted, “We did a lot of creative improvisation, thinking outside the box”. Audience members included high school students who attended the matinee performance with school groups, staff from the community living sector, families and caregivers, and researchers and staff from local universities. Mounting the show in the Massey Theatre allowed us to integrate inclusive design for co-creators and for the audience. The use of set, lighting, sound, and props were all purposeful in terms of communicating the themes derived from the initial focus groups. We also travelled the show to two conferences. One was an inclusive education conference with education leaders representing all school districts in British Columbia. The other was the World Congress on Supported Employment. This extended the research of the production across British Columbia and worldwide. The performance was video-recorded so as to be accessible beyond the live performance. A promotional video was also created that exclusively features the voices of the self-advocate co-creators describing the development process, the research process, and the themes of WDTW. This video has been widely shared in university, school district, and community education settings. Finally, of note, the WDTW program was written in plain language with summaries for each scene.

#### 4. Discussion and Conclusions

Walmsley (2023, personal communication, 28 November) discusses how inclusive research can be a developmental process. Learning to practice inclusive research has been and is a developmental process for us (academic researchers of the CIIC); we continue to learn and grow as researchers committed to collaboration and inclusion. In this discussion and informed by Walmsley and Johnson’s (2003) five principles of inclusive research, we describe strengths, tensions, and lessons learned as we engaged in a disability and devised theatre CPAR project.

##### 4.1. Relevance to People with Intellectual Disabilities and Furthering Their Interests

In line with Walmsley and Johnson (2003), the topic of WDTW, employment, had direct relevance to people with intellectual disabilities. Employment is a key aspiration for individuals with intellectual disabilities (Humber 2014; Tompa et al. 2022). Employment enhances the quality of life, improves financial wellbeing, and increases social inclusion for individuals with intellectual disabilities (Randall et al. 2022; Robertson et al. 2019). However, people with intellectual disabilities face significant barriers to labour market participation (Tompa et al. 2022). In British Columbia (BC), Canada, only 24.2% of individuals receiving community living supports reported income, and over 75% of these individuals earned less than CAD 10,000 per year with 53% of the 24.2% earning less than CAD 5000 per year (Community Living British Columbia 2019). This is in a province where recipients of the Persons with Disability Benefits have an annual earnings exemption of CAD 15,000 per year (BC Ministry of Social Development and Poverty Reduction n.d.). Given this, employment is a key priority of policy makers, community living service providers, families and supporters, and self-advocates themselves in BC. Of greater significance, however, is the importance of employment to the self-advocate actors and co-creators of WDTW themselves.

As described above, the topic itself was identified by the self-advocate actors and co-creators themselves. The direction for the play was decided by the self-advocate co-creators when they surfaced issues important in their lives. They identified their own experiences with employment as frustrating. One individual talked about struggling for any kind of advancement in her grocery store job. Several had never considered paid work as an option, yet another had many entrepreneurial aspirations but did not know how to enact them. The self-advocate co-creators believed that the performances (and videos of the play) would provide a platform to share their experiences and advance their rights to work. As one individual shared, “I think a social justice theatre piece is like. . .standing up for yourself and to fight for a good cause”. The self-advocate co-creators recognized not only the benefits the messages of play could personally offer them but also the need for a broader societal discussion about inclusive employment.

Finally, one interesting aspect of *WDTW* is that audience members included members of the disability community. In their feedback, self-advocate attendees shared what resonated with them, what they learned, and how they want to see the messages of the play reach more self-advocates, employers, caregivers, and family members.

#### 4.2. CPAR and Devised Theatre to Facilitate Inclusive Research

The development and production of disability theatre as CPAR offer a platform where SAs’ diverse ways to communicate and be in the world can be honoured and taken up as resources to the research and community (Schnellert et al. 2022; Chalachanová et al. 2020). This study demonstrates how disability theatre as CPAR can bring SAs and community partners together to research significant issues with personal and structural elements and translate and mobilize knowledge by embedding themes from the research into scenes using diverse modes of communication. *WDTW* engaged SA co-creators, theatre artists, inclusion support staff, and audience members beyond spoken language utilizing body language, sound effects and music, and lighting (Goodley and Moore 2002) to illustrate research findings. We agree with Garbutt (2009, p. 12) that disability theatre as CPAR facilitates “participation to individuals who might otherwise be disabled by the research approach taken, rather than by their ability to communicate”. In our research, we have found that self-advocates’ ability to “communicate through theatre offers new possibilities for connection and understanding, as well as a sense of agency and of pride over the work itself” (Schnellert et al. 2022, p. 482).

In addition to increased opportunities for self-advocate participation in research, increased pathways to communication, and co-creation of KT, disability theatre as CPAR offers lessons regarding non-disabled research team members’ roles in inclusive research practice. “One aspect of inclusive research that marks it out as different from ordinary qualitative research is the efforts to make transparent what roles different contributors to the research have taken on (Walmsley 2004)” (Nind et al. 2016, p. 544). We learned several lessons regarding the roles of researchers and community partners within disability theatre as CPAR. For example, we found that rotating self-advocate membership in the *WDTW* steering committee resulted in deeper participation for some who were less outgoing. The initial three self-advocates on the steering committee had communicated more involvement in the inner working of the partnership project after our first project, *RRR*. Their role on the steering committee offered them opportunities to use, be recognized for, and develop an expanded skill set (i.e., part of decision making about rehearsal schedules, travelling the show, and the research processes). Of note was when members of the Company with more profound intellectual and/or communication disabilities rotated onto the steering committee, staff who had previously worked with these individuals were surprised by the depth of insights offered and the ideas generated for marketing and promotion. This opportunity to prepare and share their insights with access to augmentative and alternative communication devices (including Zoom reaction buttons), a smaller group, ample wait time, and a previously circulated agenda led to increased recognition for their capabilities and opportunities to represent the CLS on other committees.

An overall contribution of disability theatre/CPAR within and beyond research projects is how self-advocates had opportunities to demonstrate their knowledge, agency, and skills. Across interviews with self-advocates, partners, and theatre artists, it was noted that many SAs' knowledge, insights, talents, and creativity had been underestimated—in many cases for years (Schnellert et al. 2023). In line with de Haas et al. (2022), we underscore that people with higher support and communication needs have assets and contributions to make. Meaningful inclusion thus requires creative and contextualized commitments to create new methods and practices.

Nind et al. (2016, p. 543) writes, “the process of learning to do inclusive research. . . is accentuated by the newness of the paradigm and the emphasis placed on the value of lived reality of, for example, people with [intellectual disabilities] in shaping the research goals and processes”. The iterative process of theatre development showcased the improvisational skills of SAs as they developed their characters, responded to scene partners' improvised lines, and incorporated audience reactions and feedback. Thus, we point out that the theatre creation process (devising, developing, and refining scenes) is research in itself where self-advocates draw not only from the focus group interviews but also from their own lived experience and creativity and audience feedback.

A final contribution is what we learned about mentoring the development and practice of research skills. Researchers have noted that when conducting inclusive research, often times, individuals with higher support needs remain excluded (Jones et al. 2019; de Haas et al. 2022). Nind et al. (2016) explain, “It is through involvement in the various stages of research that people learn the ‘rudiments of research methods so they can assume collaborative roles in the research’ (Bagnoli and Clark 2010, p. 103)” (Nind et al. 2016, pp. 543–44). We found that all the self-advocates enjoyed the more traditional aspects of the research—brainstorming and developing the interview questions, leading focus groups, and analyzing data for themes.

#### 4.3. Learning through Tension

We experienced several tensions in this disability theatre CPAR project. These included power dynamics, the diverse self-advocates' communication modes and needs, role clarity/conflicting goals, COVID-19, theatre accessibility, and travelling the show (reconstituting the show has many more factors to consider than travelling a traditional show). Related to praxis initiation, the theatre and inclusion facilitators sometimes moved the development phase in directions they interpreted as the desire of the self-advocates. With the self-advocates' diverse communication styles and inclusion facilitators' influence as leaders, decisions and directions were sometimes made too quickly and/or pre-emptively instead of iteratively and more democratically seeking confirmation and ongoing input from the self-advocate co-creators. Similarly, there were disagreements over how decisions should be made, especially under time pressure. Self-advocates, community living experts acting as inclusion facilitators, disability theatre facilitators, and theatre artists had several differences of opinion during the multi-year development, rehearsal, production, and performance phases (Schnellert et al. 2023). Throughout the development, rehearsal, and production phases, inclusion advocates and disability theatre facilitators raised and centred self-advocate needs that required constant tinkering with design elements, which interrupted the flow of technical and artistic decisions needed to stay on track with deadlines. COVID-19 added layers of unanticipated complexity—development online was difficult for self-advocates with little Zoom experience—in terms of using online platform elements, receiving and communicating messages about thematic content and theatre and research processes, and overall engagement and participation. Finally, we experienced physical challenges creating and mounting disability theatre productions in traditional theatres and travelling shows to community events and conferences.

In inclusive research, there will always be tensions. As Seale et al. (2015) assert, participatory research is shared space, and it is what Torre (2005) called a “messy social space” where people with different perspectives, strengths, and knowledge come together



around a shared vision. This messy space is not necessarily a threat to the CPAR process (Seale et al. 2015). Rather, in this space,

each participant is understood to be a carrier of knowledge and history; everyone holds a sincere commitment to creating change for educational justice; power relationships are explicitly addressed within the collaborative; disagreements and disjunctures are excavated rather than smoothed over, and there is a collective expectation that both individuals and the group are “under construction. (Seale et al. 2015, p. 487)

One of the benefits of disability theatre as CPAR is that tensions are recognized as sites of possibility—scenes in theatre are built from and around moments of tension. CPAR with individuals with intellectual disabilities involves developing a set of shared practices. As a group of self-advocate co-creators, researchers, theatre artists, and inclusion facilitators, we represented diverse perspectives and lived experiences—and among the self-advocate co-creators, these differences were also apparent. Thus, it is imperative to be proactive and set an expectation that there will be tensions within the research process.

McConn and Mason (2019, p. 3) summarize an international body of research that illustrates “logistical and cultural differences. . .create tensions within these potential collaborative partnerships”. Theatre scholar Applebaum (1995) refers to tensions as “stop moments”. We need to stop and explore the source of a tension, possible responses, and what we can learn. “The resolution of these challenges pushes the boundaries and in doing so opens up new and messy spaces” (Seale et al. 2015, p. 489). McDonough (2014) identified tensions related to loyalty, advocacy, and obligation in inclusive research. Developing, revisiting, and refining protocols to address disagreements; offer and receive feedback from different positionalities; and disassemble and reassemble writing materials spanning scripts to playbills to promotional materials were and are helpful. Researchers now recognize the importance of acknowledging the personal experience of inclusion from the perspectives of persons with disabilities (Cobigo et al. 2016, p. 226). In both *Romance, Relationships and Rights!* and *WDTW*, we worked to centre the self-advocates’ perspectives that required ongoing reflexivity on our power in our positionalities as the researcher, theatre artist, and/or leader.

#### 4.4. Recommendations for Inclusive Researchers

In this next section, we provide some of our learnings about inclusive research when engaging in disability theatre informed by disability justice. As mentioned in the introduction, disability justice in research centres social justice and, as such, necessitates reframing practices of access, ethics, and equity (Keifer-Boyd et al. 2018). Disability justice principles—centring the voices of those who are the most impacted, recognizing wholeness of each person, interdependence, collective access as an ongoing flexible and creative process, and collective liberation where no body/mind is left behind (Sins Invalid 2019)—all of these must inform disability theatre as a practice of inclusive research.

The following are some recommendations that aim to enhance the inclusion and success of disability theatre CPAR. Many of these learnings come from strategies that worked to enhance inclusion, access, ethics, and equity throughout the project, and others come from reflecting on the tensions in hindsight as a means of learning through reflexivity.

- (1) Commit to the principle that social justice theatre necessitates that the topic and messages come from the people most affected: lift up, listen to, follow, and highlight the perspectives of those who are most impacted by the systems of ableism and other forms of oppression (Sins Invalid 2019).
- (2) Develop, revise, and revise participation, reflection, and problem-solving protocols recognizing that collective access is contextual, improvised, and always changing (Sins Invalid 2019).

- (a) Within and across all phases of the project—e.g., research, theatre creation and rehearsal, and organizational processes—ensure intentional stop moments to reflect on whose voices are being heard.
  - (b) Establish shared commitments and revisit them when tensions arise. For example, commit to the importance of hearing from all self-advocates via their communication preferences.
- (3) Recognize the timelines needed for self-advocates to fully participate in data collection, data analysis, creation of messages and scenarios/acts/scenes, rehearsal, and theatre production and design elements ensuring that no one is left behind.
  - (4) Be aware of access needs (recognizing that this requires flexibility and creativity) when mounting the play at the home venue as well as when reconstituting aspects of the production when bringing it to different constituent groups in different venues.
  - (5) Ensure there are ongoing self-advocate consent and micro-consent processes “that are rooted in self-determination, active consent, and the needs of the collective” (Sins Invalid 2019, p. 70).
    - (a) We learned that self-advocates may wish to participate in the data collection and analysis stages but not the theatre creation and performance phases.
    - (b) We learned to set and revisit protocols for sharing ideas (to make space for everyone) and regarding physical touch within the creation process and performance (between self-advocate actors, and between facilitators and actor/co-creators).
  - (6) Scaffold the research skill development of self-advocates in all aspects of the research, offering different roles and participation access points based on tasks: “[remember] that moving together doesn’t mean that we all participate in the same way; [it’s important to value and adore] all the ways that we show up” (Sins Invalid 2019, p. 69).

Finally, it is important to note the underlying principle of collective access across these recommendations. As Sins Invalid (2019) explains, it is important to acknowledge the “iterative/repetitive/cumulative process of supporting [one another]”, meaning this is a constant process and we usually do not get it right the first time (p. 71). Thus, we need to work collaboratively “committing to our collective stake in ensuring access and striving to be accountable to each other” (p. 71).

#### 4.5. Conclusions

In conclusion, the question for those interested in inclusive research is, “How to be inclusive? And, what works best for this given project?” And as Nind and Vinha (2012) assert, regardless of methods and approaches, disability research should be authentic; should answer important questions we could not otherwise answer; should generate accessible knowledge for participants and communities; should involve the knowledge and perspective of people with intellectual disabilities; and should make a positive impact on the lives of people with intellectual disabilities. Over the past seven years, we have grown in our capacity to develop and enact disability-justice theatre as CPAR. Working with self-advocates to co-create goals, processes, and timelines together has resulted in more self-advocate ownership and agency of the topic studied and data collection and analysis; more collective access (Sins Invalid 2019); and more participatory knowledge translation and mobilization.

Future research can examine when and how self-advocates experience agency as (co)researchers. This would add further insight into how to enact Walmsley and Johnson’s (2003) call for people with intellectual disabilities to be collaboratively involved in the process of doing the research. In our own CPAR and disability theatre work, we plan to build in more reflective opportunities as a collective where self-advocates, inclusion facilitators, and theatre artists surface and address tensions across the phases of a project. We have learned that time spent mentoring self-advocate research skill development fosters confidence and adaptability when self-advocates are engaged in research activities such as

leading focus groups. Research into what self-advocates determine as themes from data and how they translate these into scenes/scenarios can prove fruitful for understanding how self-advocate perspectives and lived experience add depth to qualitative and arts-based research. Such efforts would help to see how people with intellectual disabilities exert analytical influence within research processes and outcomes (Walmsley and Johnson 2003, p. 64). Future research could also explore how increasing pathways to communication, co-creation of KT strategies, and protocols for power sharing and problem solving within disability theatre as CPAR impact the roles, outcomes, and experiences of disabled researchers. Finally, we have learned that we need to recognize from the outset that there will be tensions and issues and that we need processes—explicit shared commitments and protocols—to address them. Perhaps the most generative aspect of our research is the potential for engaging with tensions as a praxis point for disability justice. Developing research programs and productions with this in mind has transformative potential for inclusive research and practice.

**Author Contributions:** Conceptualization, R.D.H. and L.S.; validation, R.D.H. and L.S.; formal analysis, R.D.H. and L.S.; investigation, R.D.H. and L.S.; resources, R.D.H. and L.S.; writing—original draft preparation, R.D.H. and L.S.; writing—review and editing, R.D.H. and L.S.; visualization, R.D.H. and L.S.; project administration, R.D.H. and L.S.; funding acquisition, R.D.H. and L.S. All authors have read and agreed to the published version of the manuscript.

**Funding:** This research was funded by The Vancouver Foundation, grant number FOI20-3660.

**Institutional Review Board Statement:** This study was conducted in accordance with the Declaration of Helsinki and approved by the Behavioural Research Ethics Board of the University of British Columbia (protocol code H21-00127 and March 2021).

**Informed Consent Statement:** Informed consent was obtained from all subjects involved in this study.

**Data Availability Statement:** No new data were created or analyzed in this study. Data sharing is not applicable to this article.

**Acknowledgments:** We would like to acknowledge the self-advocate co-creators and actors, theatre artists, and inclusion facilitators who made this CPAR project possible. And we would like to acknowledge our partners—the Community Living Society and the Massey Theatre.

**Conflicts of Interest:** The authors declare no conflict of interest.

## References

- Applebaum, David. 1995. *The Stop*. Albany: SUNY Press.
- Bagnoli, Anna, and Andrew Clark. 2010. Focus groups with young people: A participatory approach to research planning. *Journal of Youth Studies* 13: 101–19. [CrossRef]
- Barnes, Colin, and Geof Mercer. 1997. *Doing Disability Research*. Disability Press.
- BC Ministry of Social Development and Poverty Reduction. n.d. Annual Earnings Exemption. Available online: <https://www2.gov.bc.ca/gov/content/family-social-supports/services-for-people-with-disabilities/disability-assistance/on-disability-assistance/annual-earnings-exemption> (accessed on 21 November 2023).
- Boal, Augusto. 2002. *Games for Actors and Non-Actors*, 2nd ed. New York: Routledge.
- Chalachanová, Anna, Melanie Nind, May Østby, Andrew Power, Liz Tilley, Jan Walmsley, Britt-Evy Westergård, Torill Heia, Alf Magne Gerhardsen, Ole Magnus Oterhals, and et al. 2020. Building Relationships in Inclusive Research in Diverse Contexts. *Scandinavian Journal of Disability Research* 22: 147–57. [CrossRef]
- Chen, Mel Y., Alison Kafer, Eunjung Kim, and Julie Avril Minich. 2023. *Crip Genealogies*. Durham: Duke University Press.
- Cobigo, Virginie, Roy Brown, Yves Lachapelle, Rosemary Lysaght, Lynn Martin, Hélène Ouellette-Kuntz, Heather Stuart, and Casey Fulford. 2016. Social Inclusion: A Proposed Framework to Inform Policy and Service Outcomes Evaluation. *Inclusion* 4: 226–38. [CrossRef]
- Community Living British Columbia. 2019. *Periodic Report for Employment and Data Match*. Vancouver: Community Living British Columbia, 31p.
- Conroy, Colette. 2009. *Theatre and the Body*. New York: Bloomsbury Publishing.
- de Haas, Catherine, Joanna Grace, Joanna Hope, and Melanie Nind. 2022. Doing research inclusively: Understanding what it means to do research with and alongside people with profound intellectual disabilities. *Social Sciences* 11: 159. [CrossRef]
- Decottignies, Michelle. 2016. Disability arts and equity in Canada. *Canadian Theatre Review* 165: 43–47. [CrossRef]

- Dolmage, Jay T. 2017. *Academic Ableism*. Ann Arbor: University of Michigan Press.
- Erevelles, Nirmala. 2014. Thinking with disability studies. *Disability Studies Quarterly* 43: 1–17. [CrossRef]
- Fine, Michelle, and María Elena Torre. 2021. *Essentials of Critical Participatory Action Research*. Washington: American Psychological Association.
- Garbutt, Ruth. 2009. Let's talk about sex: Using drama as a research tool to find out the views and experiences of young people with learning disabilities. *Creative Approaches to Research 2*: 8–21. [CrossRef]
- Garland-Thomson, Rosemarie. 2005. Feminist disability studies. *Signs* 30: 1557–87. [CrossRef]
- Goodley, Dan, and Michelle Moore, eds. 2002. *Arts against Disability: The Performing Arts of People with Learning Difficulties*. Plymouth: BILD.
- Goodley, Dan, Rebecca Lawthom, Kirsty Liddiard, and Katherine Runswick-Cole. 2019. Provocations for Critical Disability Studies. *Disability & Society* 34: 972–97.
- Hole, Rachele, Leyton Schnellert, and Gloria Cante. 2022. Sex: What's the big deal? Exploring individuals' with intellectual disabilities experiences with sex education. *Qualitative Health Research* 32: 453–64. [CrossRef]
- Humber, Lee Anderson. 2014. Social inclusion through employment: The marketisation of employment support for people with learning disabilities in the United Kingdom. *Disability & Society* 29: 275–89.
- Johnston, Kirsty. 2016. *Disability Theatre and Modern Drama: Recasting Modernism*. London: Bloomsbury Publishing PLC.
- Jones, Katherine Elisabeth, Shelly Ben-David, and Rachele Hole. 2019. Are individuals with intellectual and developmental disabilities included in research? A review of the literature. *Research and Practice in Intellectual and Developmental Disabilities* 7: 99–119. [CrossRef]
- Keifer-Boyd, Karen, Flávia Bastos, Jennifer Richardson, and Alice Wexler. 2018. Disability justice: Rethinking "Inclusion" in arts education research. *Studies in Art Education* 59: 267–71. [CrossRef]
- Kincheloe, Joe L. 2001. Describing the bricolage: Conceptualizing a new rigor in qualitative research. *Qualitative Inquiry* 7: 679. [CrossRef]
- McConn, Matthew, and Jillian Mason. 2019. A university and local school partnership: Utilizing tension as a catalyst for growth. *Studying Teacher Education* 15: 235–53. [CrossRef]
- McDonough, Sharon. 2014. Rewriting the script of mentoring pre-service teachers in third space: Exploring tensions of loyalty, obligation, and advocacy. *Studying Teacher Education* 10: 210–21. [CrossRef]
- McRuer, Robert. 2006. *Crip Theory Cultural Signs of Queerness and Disability*. New York: NYU Press.
- Nind, Melanie. 2014. *What Is Inclusive Research?* London: Bloomsbury Academic.
- Nind, Melanie. 2017. The practical wisdom of inclusive research. *Qualitative Research* 17: 278–88. [CrossRef]
- Nind, Melanie, and Hilra Gondim Vinha. 2012. *Doing Research Inclusively, Doing Research Well?* Southampton: University of Southampton, 73p.
- Nind, Melanie, and Hilra Gondim Vinha. 2014. Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities* 42: 102–9. [CrossRef]
- Nind, Melanie, Rohhss Chapman, Jane Seale, and Liz Tilley. 2016. The conundrum of training and capacity building for people with learning disabilities doing research. *Journal of Applied Research in Intellectual Disabilities* 29: 542–51. [CrossRef]
- O'Brien, Patricia. 2022. Inclusive research: Is the road more or less well travelled? *Social Sciences* 11: 582. [CrossRef]
- Oliver, Michael. 1992. Changing the social relations of research production? *Disability, Handicap, and Society* 7: 101–14. [CrossRef]
- Randall, Kristina N., Gerald Bernard, and Lois Durah. 2022. Association between employment status and quality of life for individuals with intellectual or developmental disability. *Journal of Applied Research in Intellectual Disabilities* 36: 270–80. [CrossRef]
- Robertson, Janet, Steve Beyer, Eric Emerson, Susannah Baines, and Chris Hatton. 2019. The association between employment and the health of people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities* 32: 1335–48. [CrossRef] [PubMed]
- Schnellert, Leyton, Leah Tidey, and Rachele Hole. 2022. Romance, relationships, and rights: Ethical considerations and dilemmas in a research-based theatre project with self-advocate co-creators and actors. *Qualitative Inquiry* 29: 295–304. [CrossRef]
- Schnellert, Leyton, Leah Tidey, RRR Co-creators, and Rachele Hole. 2023. "You have the right to love and be loved": Participatory theatre for disability justice with self-advocates. *Qualitative Research* 23: 467–85. [CrossRef]
- Seale, Jane, Melanie Nind, Liz Tilley, and Rohhss Chapman. 2015. Negotiating a third space for participatory research with people with learning disabilities: An examination of boundaries and spatial practices. *The European Journal of Social Science Research* 28: 483–97. [CrossRef]
- Sherry, Mark. 2007. (Post)colonising Disability. *Wagadu: A Journal of Transnational Women's & Gender Studies* 4: 14.
- Sins Invalid. 2019. *Skin, Tooth, and Bone: The Basis of Movement Is Our People*, 2nd ed. Available online: <https://www.sinsinvalid.org/disability-justice-primer> (accessed on 21 November 2023).
- Tidey, Leah, Leyton Schnellert, and Rachele Hole. 2023. "Everyone should get the chance to love": Sexual health education and disability research-based theatre with self-advocates. *The Canadian Journal of Human Sexuality* 31: 198–206. [CrossRef]
- Tomba, Emile, Daniel Samosh, and Alecia M. Santuzzi. 2022. The benefits of inclusion: Disability and work in the 21st century (guest editorial). *Equality, Diversity and Inclusion* 41: 309–17. [CrossRef]

- Torre, Maria Elena. 2005. The Alchemy of Integrated Spaces: Youth Participation in Research Collectives of Difference. In *Beyond Silenced Voices: Class, Race and Gender in United States Schools*. Edited by Lois Weis and Michelle Fine. Albany: State University of New York Press, pp. 251–66.
- Walmsley, Jan. 2004. Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities* 32: 65–71. [[CrossRef](#)]
- Walmsley, Jan. 2023. The Open University, London, UK. Personal communication.
- Walmsley, Jan, and Kelley Johnson. 2003. *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. London: Jessica Kingsley Publishers.

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