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# Approaches Perceived to Promote Allyship Between Researchers and the Autistic Community

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UNIVERSITY OF CALGARY

Approaches Perceived to Promote Allyship Between Researchers  
and the Autistic Community

by

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A THESIS

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## **Abstract**

Previous research regarding autistic people has largely been limited in regards to its meaningful engagement with the autistic community, particularly in terms of determining research priorities and engagement in research planning and processes. This tendency of exclusion in such research opportunities may result in diminished community understanding of autism from the direct perspective of autistic people themselves, and of a potential lack of social and community inclusion overall. This study addressed the question, ‘what are perceived to be optimal approaches of promoting allyship between researchers and the autistic community?’ Research aims were to explore and promote allyship and collaboration between the research and autistic community in (a) identifying perceived means to build allyship in autism research, and (b) demonstrating and exploring an instance of meaningful engagement of autistic adults in research. Two mixed focus groups and an email interview were facilitated with a total of 6 autistic individuals, 4 autism researchers, and 2 individuals who identified as both autistic individuals and researchers. Methodologic decisions were made according to principles of participatory research and guided by a critical theoretical framework. Study results included the identification of approaches for allyship in autism research, including (a) a mediation or advisory group that would serve to ‘bridge’ the autistic community and autism researchers; (b) mentorship opportunities for autistic individuals aiming to access research information and experience, as well as for researchers aiming to inclusively engage with the autistic community; and (c) a partnership between community members and a research or university setting.

*Keywords:* autism, autistic community, allyship, participatory, critical social work

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## **Dedication**

To Chelsey Drapaka (December 18 1983 - December 6 2020) who made important contributions to this research, bringing a genuine community spirit that will continue to make an impact beyond these pages.

To the people who enthusiastically joined these discussions and brought life to the idea of simply 'coming to the table.'

## **Glossary of Terms**

*Allyship:* In this thesis, allyship refers to relational engagement that moves beyond simply research partnership or a specific transactional communication. It entails an attempt to develop a genuine understanding of the person with lived experience and, in this case, their perspectives and preferences regarding existing and future autism related research.

*Autistic community:* Although the larger autism community sometimes includes persons associated with, and supportive of, autistic people or who regularly engage and/or work within the area of autism (i.e., service providers, family members, policy makers, community or government workers etc.), the autistic community discussed in this thesis, refers specifically to self-advocates and not the associated roles and relationships that exist outside of the autistic community.

*Participatory Research (PR):* “An methodological approach to research in communities that emphasizes participation and action” (SAGE Publications, 2021). In this thesis, PR includes its many iterations and evolutions, including community-based participatory research (CBPR), participatory action research (PAR) and community academic partnership (CAP).

*Self-advocate:* A self-advocate is an individual with lived experience. In this thesis, self-advocates are individuals with personal lived experience (i.e., autistic individuals), whether verbal, minimally verbal or non-verbal.

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## Chapter 1: Introduction

As a result of increased societal recognition regarding oppression experienced by people with disabilities, as well as the momentum created by peripheral social justice movements (i.e., LGBTQ2S+ rights, Black Lives Matter, #MeToo movement), there has been an emerging advocacy movement seeking more intentional, integrated engagement of the autistic<sup>1</sup> community in autism research. Previous research regarding autistic people has largely been limited in regards to its meaningful engagement with the autistic community, particularly in terms of determining research priorities and engagement in research planning and processes. This tendency of exclusion in research opportunities may risk diminished community understanding of autism, and may contribute to a lack of social and community inclusion for autistic people in key elements that affect their lives and future. Where autistic people have participated in research, it typically has reflected researcher-led designs. The few studies that reflect an effort to more integrally involve autistic people have been guided by approaches such as Participatory Research (PR) (including community-based participatory research [CBPR], and community-academic partnerships [CAPs]) but often with restrictions to participant engagement (Jivraj et al., 2014).

Recent emancipatory approaches (Chown et al., 2017; Hart et al., 2017; Martin, 2015) have emerged that challenge the traditional role of autistic people as research ‘subjects’ or participants, and provide a new direction in relationships between the autistic community and

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<sup>1</sup> This thesis uses identity-first language (e.g., autistic person) in alignment with autistic people who have communicated this as their preference over person-first language (e.g., person with autism) (Brown, 2011; Bottema-Beutel et al., 2020; Gernsbacher, 2017; Kapp et al., 2013; Kenny et al., 2016; Sinclair, 1999).

autism researchers. There is increased critical and collaborative work taking place between academics and the community. For example, work conducted by the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) and the Participatory Autism Research Collective (PARC), illustrates enhanced opportunity for the community to gain momentum in developing and maintaining collaborative practices between the autistic and academic communities. This advancement has largely resulted from promoting the autonomy, identity and elucidation of the perspectives of autistic people in research endeavours and has emphasized the 'space' for this involvement on autistic people's own, and/or on mutually agreed upon, terms.

### **Emergence of 'Allyship'**

An emerging relational notion and role in this work is an 'ally' who can be characterized as someone who offers their support to members of a population with an emphasis on meaningful actions with, or on behalf of, people with lived experience, along with an understanding of the ally's power, social location and privilege in the relationship as well as in society overall (Bishop, 2015). Thus, allyship arguably moves beyond merely support and partnership, and attempts to construct a genuine way of 'being' with others – in this case, autistic people – in the community.

Allyship is an inherently challenging concept and achievement, as a researcher cannot just independently self-identify as an ally; rather, trust must be built with the autistic community through meaningful actions and community engagement over time. Similarly, a research study or research team might claim to be 'participatory' or 'inclusive', yet not truly and deeply

demonstrate the values that would naturally accompany these approaches (i.e., transparency, community mindedness, etc.).

Allyship emerges as an intentional but also organic process. It is inherently relational and non-prescriptive in nature as it is enacted between a group or community and an individual who may be trying to ‘support’ or ‘stand with’ the community or individual. The ambiguous and contextual nature of this relationship is something that necessitates open and honest discussion and exploration.

### **Research Question and Aims**

This research aims to explore and promote this notion of allyship and authentic collaboration between the research and autistic communities by (a) identifying perceived means to build allyship in research, and (b) demonstrating meaningful opportunity for the engagement of autistic adults in research.

In addressing the current lack of in-depth community involvement in research, and towards moving current relationships forward between autistic people and others within the community, this research addresses the question: ‘what are perceived to be optimal approaches of promoting allyship between researchers and the autistic community?’ The aim of the study was to identify potential approaches for allyship in autism research, and offer information to potentially create safe, open, yet critical space for exploring allyship between autistic individuals and researchers. In advancing aims toward social justice for the autistic community, this work strives to amplify the perspectives of autistic people.

## **My Journey to Allyship: An Evolving Path of Research and Social Work**

In line with the theoretical framework used in this thesis which emphasizes the importance of critical reflexiveness (Goodley, 2013), I would like to begin by acknowledging myself and my location within the substantive area of this research. To start, I am not autistic. On our human spectrum of neurodiversity, I would be considered neurotypical. There is a historical tendency for neurotypical researchers to conduct research ‘on’ autistic people (Cascio et al., 2019), and I am tentatively placing myself in those shoes, while striving to work ‘with’ the autistic community. As well, I do not self-proclaim to be an ally, but certainly try to be. As an aspiring social worker, I acknowledge that this includes “respond[ing] to needs of...groups, and communities, and address[ing] barriers and injustices in organizations and society” (Canadian Association of Social Workers, 2008).

Initially, I was an aspiring mainstream English and music teacher. I spent two years teaching in London, United Kingdom, and was exposed to a range of educational approaches including segregated ‘special needs’ classrooms, inclusive classroom settings, and a ‘re-integration’ school for students who have been removed from mainstream classrooms due to behavioural/emotional challenges, and were subsequently being prepared to re-enter mainstream education.

Eventually this led to being placed at a school for autistic teenagers who were transitioning from educational curriculum to vocational and community living opportunities. The class to which I was assigned consisted of students who required quite significant supports and communicated non-verbally – who I would spend the next two years getting to know. This

was my first experience working with, and alongside, autistic people, as well as witnessing ways that schools, families and communities attempt to, yet variably, support and engage autistic individuals. The impact of these relationships and lessons learned continue to guide me in this work today.

Upon returning to Alberta, Canada, in hoping to learn more and *connect some dots* from what I experienced in London, I worked with a local service provider that offered supports generally to newly diagnosed autistic children and their families. Around this time, I learned about social work and had an ‘*a-ha!*’ moment. I *googled* ‘autism’ and ‘social work’ in Edmonton and came across Dr David Nicholas. I called Dr Nicholas and he said ‘call me David’, and the rest was history. I was ultimately accepted into the Master of Social Work (MSW) program, and began working as a research assistant with Dr Nicholas.

Over the four years as a research assistant, several learnings took place which led to the topic of this thesis, most notably (a) research can be incredibly important and insightful, but is often not widely read or understood by others who could be impacted by it; and (b) many autistic participants were interested in learning more about research in this area, but there was not a clear path for these conversations to occur, nor were there easy ways for these relationships to be developed, let alone sustained.

While working on a variety of autism-related studies I had the honour of meeting autistic self-advocates across Canada, including many in Edmonton, Alberta, who were interested in becoming more involved in local research opportunities, and who had a general interest in being involved in discussions around existing research. One such research project led to some

informal follow-up discussions with past participants on how aspects of the project could be sustained or further developed. These discussions ultimately led to the question of how the autism research community can better collaborate and partner with the autistic community; and furthermore, how these kinds of collaborations could be sustained and develop into a meaningful relationship. This strong interest in seeking a more meaningful and engaged relationship with autism research, as communicated by autistic self-advocates, justified my motivation to explore and advance the notion of allyship. This also seems warranted in that, despite the presence of various frameworks for participatory research, autistic individuals still sometimes feel 'left out' of the process. Thus, the notion of allyship may challenge the academic community to think beyond merely specific participatory approaches, and more towards authentic relationship.

In reflection, I have been privileged to experience all the learning described above. Moreover, I have met many amazing people along the way who inspire me to live my life as a kind and curious visitor and to engage in further development towards allyship.

### **Outline of Thesis**

This thesis consists of the seven chapters that follow. Specifically, in the next chapters, I focus on the literature and theory relative to this area of inquiry, how the research was planned and unfolded methodologically, and what has been learned through data collection and analysis. Finally, I reflect on the thesis journey and how it has advanced learning on this topic. I further reflect on the results and their integration with the literature, and consider practical and research implications and steps forward.



The specific topics of these upcoming chapters are as follows. Chapter 2 entails the literature review. In Chapter 3, I describe the critical theoretical framework that serves as a frame for this inquiry. Chapter 4 provides a description of the methodology (participatory research) and methods (focus groups, interviews and thematic analysis) of this thesis research. Following this, I outline what was shared by focus group and interview participants (Chapter 5), and share commentary, discussion and next steps (Chapter 6), before summarizing the work as a whole and seeking a broader integration of the findings with the literature (Chapter 7).

## **Chapter 2: Literature Review**

This literature review will outline relevant research that highlights some key collaborative, participatory and emancipatory research carried out by and with the autistic community. In examining the notion of allyship between researchers and the autistic community, this review provides an overview of approaches that have been implemented, and identified steps forward in building collaborative relationships between researchers and the autistic community.

This review will describe emergent shifting in collaboration between autistic individuals and autism researchers by highlighting the following areas: (a) differing interpretations of participatory research (PR); (b) a shift in autism research towards evolving definitions of Community-based Participatory Research (CBPR), including within experimental research designs; (c) further movement towards Participatory Action Research (PAR); (d) expansion into Community-Academic Partnerships (CAP); (e) emancipatory research led by the field of critical disability studies; and (f) recent international work demonstrating the continued focus towards the full inclusion of the autistic community in autism research.

### **Iterations and Interpretations of Participatory Research (PR)**

Existing literature regarding the relationship between researchers and autistic individuals varies in approach, from a positivist notion of participant as ‘subject’ (e.g., as commonly found in biomarker research), to participatory approaches where the participant is located as a ‘partner’ or ‘contributor’ (Fletcher-Watson et al., 2019; Jivraj et al., 2014; Nicolaidis et al., 2011,

Nicolaidis, 2019), to more recent discussion of emancipatory research in which the autistic individual is the ‘researcher’ or ‘author’ (Chown et al., 2017; Hart et al., 2017; Martin, 2015).

Despite commonalities between studies that adopt a participatory approach (e.g. general inclusion of stakeholders in phases of research conceptualization, planning, implementation and knowledge translation), there exists a range of differences in how and to what extent a ‘participatory’ approach is practiced. For example, SAGE Research Methods defines PR as “an methodological approach to research in communities that emphasizes participation and action. It seeks to understand the world by trying to change it, collaboratively and following reflection” (SAGE Publications, 2021). Despite definitions like this providing guidance to researchers, a scoping review by Jivraj et al. (2014) on the use of PR in autism and other neurodevelopmental disabilities found an overall lack of meaningful participant involvement, with the exception of studies published from a self-advocate led organization in the United States. Of the seven studies that were included in the review, five studies involve people with intellectual disabilities (ID), while the remaining two studies involve autistic individuals. The five studies pertaining to people with ID were found to contain differing standards of what it means to conduct PR, with all five studies not consulting with self-advocates on methodology and only one study including self-advocates in the creation of the research question. The later phases of data collection, analysis, and knowledge translation include more self-advocate participation (four out of five studies involve participants in data collection, all studies involve participants in analysis, and three out of five studies involve participants in knowledge translation) (Jivraj et al., 2014).

Despite PR being the overall framework for the studies identified in Jivraj et al. (2014), control of the research initiation, topic, and way of questioning were noted to be led by the researchers.

Upon examination, these studies that have adopted a PR approach actually lack participant involvement, which causes the concept of PR to take on a more hollow meaning in application. Rather than PR being a meaningful way in which participants have engaged in the research, participatory principles play a minor role in particular studies to date, despite social change and social action being key elements of PR (Chown et al., 2017). Jivraj et al. (2014) highlight a gap in collaboration between researchers and the autistic community, demonstrated by the small number of studies available to be reviewed, and the lack of quality or depth of collaboration in the majority of reviewed studies, thus providing an impetus for the further discussion and development of community partnerships.

### **Community-Based Participatory Research (CBPR)**

Although there are examples of PR that demonstrate limited engagement of autistic participants (as described above), examples of more expansive or comprehensive engagement in autism research also exist. For example, Nicolaidis et al. (2011, 2013) demonstrated participant engagement in multiple phases of research, including in forming the research question, choice of methodology, data collection, analysis and knowledge translation, while also involving self-advocates in article authorship. Nicolaidis et al. represent the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), and follow a CBPR framework, describing it as:

an approach to scientific inquiry in which scientific professionals and members of a specific community work together as equal partners to develop, implement, and disseminate research. As a form of action research, CBPR projects aim to make changes in the world that are desired by the community (AASPIRE, 2020, What is Community-based Participatory Research section, para. 2).

### ***CBPR and Biomarker Research***

A potentially conflictual area for collaborative partnerships is in the field of biomarker research (i.e., research on biological data). As described by Pellicano (2014), research in the UK is predominantly focused on biomarkers as well as on cognitive and biological aspects of autism. This emphasis on biomarker research is criticized by participants in the study by Pellicano (2014) due to what is viewed as the relative or consequent neglect of research addressing quality of life and lived experience among autistic people. Nicolaidis et al. (2011, 2013, and 2015) and the overall work of AASPIRE is perceived as a response to this larger emphasis of causation research, and focuses on self-advocate led priorities which, to date, have included improving access to health care (Nicolaidis et al., 2013; 2015), increasing community participation in autism research (Nicolaidis et al., 2011), and investigating experiences of violence against people with developmental disabilities (Platt et al., 2017), all of which were determined by self-advocates within AASPIRE to be priority research topics for autistic individuals.

A study by Yusuf and Elsabbagh (2015) offers an example of CBPR being utilized in research on autism biomarkers. While some self-advocates may find this collaboration to be problematic, it offers a range of perspectives within the autistic community whereby some may

support research on causation whereas the adult autistic community largely favours a focus on neurodiversity and disability rights (Pellicano, 2014).

Along with highlighting potential challenges to the use of CBPR in biomarker research (i.e. disagreement on who should be represented, the question of how to best work with the community if study results are unpredictable or unexpected, and a risk of decreased internal validity), Yusuf and Elsabbagh (2015) identify three ways that CBPR can be beneficial for biomarker research: (a) communication of stakeholder perspectives, (b) increased collaboration to improve research priorities, and (c) increased collaboration to improve research design. This research by Yusuf and Elsabbagh (2015) complicates findings from Pellicano (2014) who report discrepancies between the high rates of biomarker research compared to the differing research priorities of stakeholders, including self-advocates. The stakeholder perspectives highlighted by Pellicano (2014) suggest that research addressing quality of life for autistic people should be prioritized over biomarker research. Yusuf and Elsabbagh (2015), however, broaden this notion by carrying out CBPR in biomarker research.

Although Yusuf and Elsabbagh (2015) and Pellicano (2014) are writing from different contexts (the former from Canada and the latter from the UK), the online forums for autistic debate over the relationship between the autistic community and biomarker research can be understood to have international significance (Nicolaidis et al., 2011).

**Balancing Differing Research Priorities.** Consistent with findings of Jivraj et al. (2014) which identify a lack of meaningful partnerships between researchers and the autistic community, Pellicano (2014) describes a resistance by the research field to collaborate with

autistic individuals, citing the 'expert' stance of researchers, the possible challenge of integrating many different perspectives from the community, the possible challenge of resolving disagreements, and the belief that autistic individuals would have strong opinions that would be difficult to manage (p. 202). A key finding from Pellicano (2014) is that autistic adults report feeling excluded from research and note a lack of reciprocal relationships in research. To better understand stakeholder research priorities, Pellicano (2014) identifies some key priorities for future research, including studies which (a) highlight relevant services to the community; (b) create evidence-based approaches for services relevant to autism; and (c) pertain to social and community inclusion for autistic people. These priorities, however, are shown to be in contrast with the current focus of autism research in the UK, which is reported to be 56% related to brain, biology and cognition, and only 5% related to services for autistic people (Pellicano, 2014, p. 200). This contrast in research priorities is also demonstrated by a researcher interviewed in the study by Pellicano (2014) who expressed, "people making judgments about research and research funding 'have to be other scientists'" (p. 202). This sentiment can be compared with research priorities expressed by the autistic community and reported by Pellicano (2014), which includes "understand[ing] the place of autistic people in society" (p. 201).

### **Participatory Action Research (PAR)**

In addition to CBPR, other PR approaches found throughout autism research include (a) action research, which is concerned with elements of researcher engagement (Bigby & Frawley, 2010), and (b) Participatory Action Research (PAR) (Timmons et al., 2011; Conder et al., 2011). PAR, as defined by Conder et al. (2011), "acknowledges the need to include participants

throughout the project, accept that each person has knowledge that is of value, agree that all participants can learn from each other, and that power should be shared” (p. 40). Conder et al. (2011) also acknowledge “a sense of ownership” (p. 40) by the participants, a relevance to the lived experience of the participants, and a “reciprocal relationship” (p. 40) between researchers and participants.

### **Community-Academic Partnership (CAP)**

Another approach to researcher-community relationships has been described as Community-Academic Partnership (CAP). While seemingly interchangeable with CBPR in the way that both imply participation of the community, CAP implies a more intentional relationship between the community member (who would traditionally be the research ‘subject’) and the researcher with allegiance/connection to an academic institution. Meza et al. (2016) define CAP as “having equitable control, a cause(s) that is primarily relevant to the community of interest and aim to achieve a goal(s), and involve community members...that have knowledge of the cause, [including] academics and researchers” (p. 794). While utilizing a CBPR framework, Nicolaidis et al. (2011) define their associated organization – AASPIRE – as being an Academic-Community Partnership (presumably interchangeable with CAP). Nicolaidis et al. (2011) describes CBPR as seeking to “equalize power between academics and members of marginalized or oppressed communities” (p. 147). Meza et al. (2016) describe challenges to a CAP approach as being possibly requiring a large time commitment, complexities with funding, and challenges with communication (p. 794).



It is important to note that, despite Meza et al. (2016) describing their use of CAP with the autism community, they do not explicitly define the term ‘stakeholder,’ and instead presume it to consist of local agencies, including CEOs, supervisors, practitioners and a researcher. Comparing the CAP approach taken by Nicolaidis et al. (2011, 2013, and 2015) (i.e., leadership and collaboration with autistic individuals), there appears to be a substantial difference in understanding and application of CAPs.

### **Emancipatory Research**

There has increasingly been a movement towards emancipatory aims in participatory approaches, including CAPs and CBPR. A further step towards fuller, meaningful partnership has been the exploration of emancipatory research, which is characterized by the individual who would be the participant or subject in traditional approaches to research, becoming the research lead and making key decisions on all aspects of the research project (Martin, 2015). With the continued development of emancipatory and participatory approaches, there is an increased sense of community and advocacy, which has potentially contributed to an even greater push for inclusion and leadership for autistic people in all areas of life, including research. Martin (2015), Chown et al. (2017), and Hart et al. (2017) discuss the use of an emancipatory approach in autism research, demonstrating the shift that has occurred from a focus on participation and participatory approaches, to emancipation and leadership on what matters to people with lived experience.

### *Emancipatory Compared with Participatory*

Martin (2015) explores the boundary between emancipatory and participatory research (PR), describing how collaborative teams in emancipatory research possess relatively more control over all phases of research. This differs from PR, which may place greater emphasis on participation in specific aspects of the research. CAPs, on the other hand, may place more emphasis on aspects of partnership between researchers and stakeholders (Meza et al., 2016). Hart et al. (2017) also differentiates between participatory and emancipatory approaches, stating, “While participatory research includes the voices of individuals with disability, emancipatory research positions them to guide the entire project” (p. 834). In this approach, researchers (who may or may not be a member of the stakeholder or autistic community) intentionally place themselves outside of a leadership role, while simultaneously placing stakeholders in leadership positions, thus ‘emancipating’ individuals from former positions of research subject, participant or partner.

While problematizing the notion of a clear boundary between participatory and emancipatory research, Chown et al. (2017) further delineates between the two, describing emancipatory research as being an extension of PR. Together in emphasizing the importance of meaningful empowerment and the relinquishment of positivist academic control, these approaches seemingly offer emancipatory research as being a next step from, or expansion of, PR.

### *Emancipatory as Defined by Autistic Individuals*

A key element of emancipatory research is the aspect of leadership and control. Martin (2015) explores the issue of neurotypical-initiated research being classified as emancipatory. The author (himself a neurotypical researcher) asks the question of whether his involvement in the research, despite each phase of the project being led by self-advocates, makes the research non-emancipatory, or somehow less emancipatory than research initiated by an autistic self-advocate. Despite the author identifying as non-autistic, this research was considered emancipatory from the perspective of the autistic participants. This finding is transformative in suggesting that the autistic community indeed can decide for themselves if the research they are involved in is emancipatory, participatory or perhaps something else altogether.

Similarly, in their ethnographic research based on interviews and field observation, Hart et al. (2017) concludes that an emancipatory approach allows for flexibility in its use of methods. While there is inevitably preconceived notions held by researchers aiming to 'do' emancipatory research, the reflexivity inherent in this approach allows for the authors to reflect that it is difficult to claim a purely emancipatory approach due to the nature of power relationships influencing the result. Chown et al. (2017) expands on the exploration of emancipatory research conducted by Martin (2015). While Martin (2015) struggles with the notion of emancipatory research as involving both autistic and non-autistic participants, Chown et al. (2017) embraces this concept, with the authorship/research leadership represented by both groups.

### ***A Framework for Emancipatory Research***

Aiming to develop a framework for future emancipatory research, Chown et al. (2017) provides the following guidelines for emancipatory work: (a) the question or issue being researched is of priority to, or confirmed with, autistic individuals; (b) the research overall must be guided by a social model of disability (e.g. barriers exist because of structures in place by the dominant society); (c) the research project is owned or co-owned by members of the autism community; and (d) autistic people must perceive that the research will lead to better life outcomes (p. 726-728). Considering the stakeholder research priorities reported by Pellicano (2014) (i.e., a need for increased research on topics relevant to the lived experience of autistic people), and the challenges of conducting participatory scientific research discussed by Yusuf and Elsabbagh (2015) (i.e. disagreement on who should be represented in stakeholder research), this framework by Chown et al. (2017) provides a culmination of differing perspectives found across the previously described literature in this larger review. While this framework may not fully align with the values and preferences of all stakeholders involved in autism research, it provides research priorities from a lived experience and autistic perspective – information potentially worthy of consideration by the autism research community.

### ***Emancipatory and Beyond***

A further push towards emancipatory research, and what could be considered a postmodern version of an emancipatory approach, is provided by Benham and Kizer (2016) in the form of a visually poetic work examining the experience of an autistic individual in academia. This study moves beyond descriptions based on participatory (Jivraj et al., 2014;

Meza et al., 2016; Nicolaidis et al., 2011) or emancipatory (Chown et al., 2017; Hart et al., 2017; Martin, 2015) research. By ‘cripping’ (a critical disability term referring to the action of taking back from dominant society) the space of an academic journal, which would typically be space awarded to studies that follow a prescribed research design, Benham and Kizer (2016) challenge the assumed authority that autism research has had over autistic people. This publication provides an emotional and poetic response to a tradition of positivism and research that is not of priority to many autistic people, as noted by Pellicano (2014). Benham and Kizer (2016) write:

Our experiences have been structured for us, told to us, interpreted by others through a variety of metaphorical and figurative means: Autism as kidnapper, Autism as a disease, Autism: a thing to be combated, Autism: they’re prisoners in their heads, among so many others. Thus, in this space, we crip up, we Autistic up, we reclaim the figurative, the visual, the non-literal as our own. (p. 78)

While this kind of critical academic work may be initially limited to the field of critical disability studies, the influence of similar thinking in broader academic circles will be important to consider in the further development of researcher and self-advocate allyship.

### **Recent Work on Guidance for Inclusion of the Autistic Community**

In recent years, there has been an increase in the number of projects moving towards inclusive and collaborative research practices with the autistic community. The Autism Research Ethics Task Force, based in Montreal, Canada, have published a report (Cascio et al., 2019), directed to researchers, that provides recommended practices for inclusion of autistic participants in research. Their work is centred around five guiding principles regarding ethical

research: “1) respect for holistic personhood; 2) acknowledgement of lived world; 3) individualization; 4) focus on researcher-participant relationships; and 5) empowerment in decision-making” (Cascio & Racine, 2018). Their report highlights reflections and suggestions for researchers to consider when involving autistic participants in the “planning, doing, and sharing” (Cascio et al., 2019, p. 24) of research.

In the United Kingdom, Gowen et al. (2019) similarly have provided a number of recommendations aiming to “improve the experience and participation opportunities that autistic people have throughout the research process” (p. 31). The Participatory Autism Research Collective (PARC) is another UK-based example of autistic and neurotypical people coming together to determine how to best collaborate. PARC is described as aiming to “build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise” (Milton et al., 2019, p. 82). Additionally, UK-based Fletcher-Watson et al. (2019) describe the development of a resource for autism researchers called Shaping Autism Research UK, which “covers principles for doing research *with* autistic people, rather than *on* or *about* them” (Pellicano et al., 2017, p. 3).

In the United States, AASPIRE developed guidelines to serve as “practical recommendations for including autistic individuals as research partners, research participants, or both” (Nicolaidis et al., 2019, p. 2008). The group Autistic Adults and other Stakeholders Engage Together (AASET), also based in the United States, held a conference focused on the topic of autistic involvement in research. Discussion at this conference highlighted the necessity of researchers to nurture trust at the community level by:

[I]nvolving the community in the entire research process; Ensuring that autistic adults are compensated appropriately for their intellectual contributions; Ensuring that the feedback loop to the community about research outcomes and activities are intact and providing information about research outcomes in a timely manner (AASET, 2017, p. 6).

And in Australia, the Cooperative Research Centre for Living with Autism (AutismCRC) has developed a practice guide and checklists for conducting ‘inclusive research’ (AutismCRC, 2016).

### **Summary**

Engagement in research between autistic individuals and autism researchers has evolved from a varied and loosely understood set of approaches, to PR (including a movement for expanded collaboration in CBPR and CAPs), and more recently, to a critical emancipatory approach focused on the centering on, or highlighting of, autistic perspectives (See Chapter 4 for the elements of PR utilized in this thesis research). Examples of recent and ongoing collaboration speak to the continuously growing expectation that the call for ‘nothing about us, without us’ is genuinely respected within autism research.

### **Chapter 3: Theoretical Framework**

In this chapter, I will outline key constructs and socio-historical movements that have informed this study. Specifically, theoretical and discursive constructs and approaches that undergird this work comprise: critical reflexivity, the Disability Rights Movement, the Social Model of Disability including notions of '*nothing about us, without us*', the International Classification of Functioning, Disability and Health (ICF), the Neurodiversity Movement, Critical Disability Theory, Intersectionality, Crip Theory, DisCrit Theory, notions of 'writing back', and Profession Allied to the Community (PAC). Each of these core, and in some cases integrated, elements to this work, are described below.

This study reflects a critical theoretical perspective, constituting multiple, yet rooted and connected, critical theories. This chapter will outline and describe the critical theories that can be perceived to resonate with the topic of allyship in autism research. Beginning with an overview and origin of critical theory, a description follows of its connection to the Disability Rights Movement and the implications that followed, including the creation of the International Classification of Functioning, Disability, and Health (ICF), the Neurodiversity Movement, and critical disability theory(ies). A critique and potential limitations of critical theory are discussed, followed by possible implications of identifying critical theory as a frame for this research.

#### **Critical Theory**

Critical theory does not seek to be associated with one theory or one community, but rather makes an all-encompassing impact through a vast association of theories and identities. Reflected in structural, feminist, anti-racist, critical disability theories, and anti-oppression,



critical theory is an inherently multidisciplinary combination of theories that challenge and critique typically dominant approaches (Agger, 2006). While critical theory manifests uniquely across disciplines, it also tends to share common foundational values that uphold it as being ‘critical’ of dominant ideologies, approaches and beliefs. When a practitioner is being critical, there is an understanding that the individual will contain “a sense of self-appraisal; reassessing where we have come from, where we are at and where we might be going” (Goodley, 2013, p. 632).

The potential for critical theory was realized by activists and philosophers in the 1960s in which elements of the theory were eventually adopted by the Disability Rights Movement. First moving from a medicalized model to a social understanding of disability (Oliver, 1990), followed by an attempt to blend the two perspectives (World Health Organization, 2002), these approaches have opened up dialogue that has resulted in the Neurodiversity Movement, critical disability studies, and the many intersections between these approaches, including crip (queer and disability) and DisCrit (race and disability) theories.

Agger (2006) outlines common traits of critical theory as being (a) a general resistance to positivism; (b) a belief in progress based on current and past oppression; (c) a view of oppression as being structurally sustained; (d) the maintenance of oppression through the societal misperception of a lack of choice, (e) the potential for choice existing within the action and belief of each individual; (f) the belief that increased knowledge of structural oppression will serve to liberate; and (g) a belief that this possible liberation occurs through every day changes and awareness, as opposed to through “revolutionary expediency” (p. 5).

Connecting this to practice, Fook (2002) summarizes critical theory as being rooted in a structural understanding of inequity, a critical perception of all aspects of society, and a focus on emancipation and social change. This structural critique of society forces the critical practitioner to be transparent about their biased allegiance towards dismantling inequity, while some research, especially in traditional experimental research, may rely on a more objective approach which attends less to such critique (Kincheloe et al., 2018).

### ***Critical Reflexivity***

While not deliberately included by Agger (2006) as an essential element of critical theory, it seems remiss to conduct research from a critical lens without reflectively considering oneself as a researcher, including the experiences, biases and privilege brought into, and wrought from, the research. Fook (2002) describes how critical theory challenges inherent approaches in research “by drawing attention to the perspective of the knower, and how it influences what is known and how it is known (reflexivity)” (p. 33). Without this element of critical reflexivity, research claiming structural or critical aims may be questioned as the researcher would not be examining the very system that they are operating within. Strega and Brown (2015) emphasize this issue, stating, “[Reflexivity] requires that we intentionally, consciously, and repeatedly bring our awareness to the question of what influences our perceptions, conceptions, and responses (internal and external) throughout the research process, from inception to dissemination” (p. 8).

While this description of reflexivity places the practice and responsibility of being reflexive on the researcher, a critical approach would further invite reflexivity among all involved in the research enterprise. Acknowledging that we all bring ingrained beliefs and

epistemologies from our positionality and personal experiences, these beliefs are salient to research location, yet may be normalized and accepted without question (Strega & Brown, 2015). A critically reflexive approach can offer resistance to this ‘auto-pilot’ thinking, thus offering a way of becoming more critically self-aware.

### ***Origins of Critical Theory***

Critical theory has its foundation in the ideology of resistance. In this sense, the fundamental aspects of critical theory (i.e. emancipation, anti-oppression, etc.) can be understood to originate wherever an individual or group has been aware of their subordinate position relative to a dominant individual or group, and has developed a plan to change their circumstance. A foundational example of this was accomplished by Karl Marx in the mid-1800s with publications on communist ideology in a movement towards the working class (proletariats) resisting capitalism (bourgeoisie). Members of the ‘Frankfurt School’ (a group of scholars in the 1930s at the Institute for Social Research, University of Frankfurt) articulated critical theory as a version of “neo-Marxism” (Agger, 2006, p. 78).

The Marxist roots of critical theory can be seen as having particular relevance to the research topic outlined in this thesis. Marxism speaks directly about the working class proletariat and their struggle to overthrow the privileged bourgeoisie who controlled the lives and well-being of the proletariat by owning and controlling the physical means of production (i.e. technology associated with factories and the factories themselves). A parallel can potentially be seen between recent conflicts relative to the current state of researcher-led (i.e., traditional) research. In this sense, the researcher (the ‘knower’) traditionally has become the

owner of knowledge, not only in the sense of conducting the research on the subject (the ‘known’), but also in the ability for the researcher to access funding and disseminate knowledge through publication, with personal benefits of career building. Metaphorically applying a traditional research approach, the research participant (subject) can be seen as being akin to the proletariat – disempowered and with little to no ownership of the means of production (research) despite the ramifications, power and influence that research has on the policies, procedures and approaches that have direct impact on the community.

### **Disability Rights Movement**

The momentum of change created by the multiple resistive movements of the 1960s (i.e. Civil Rights Movement, Women’s Rights Movement) coincided with the beginnings of the Disability Rights Movement. Following a policy of institutionalization from the early twentieth century – perceived as a way of benefiting dominant society as “a means of controlling non-viable workers” (Goodley, 2013, p. 633) – society began to slowly transition to a period of deinstitutionalization from about the 1970s onwards, with a demand for increased social inclusion and community engagement (Pelka, 2012). These social movements culminated in the Canadian Human Rights Act (1977), Charter of Rights and Freedoms (1982), and, in the United States, the Americans with Disabilities Act (1990), all of which enshrouded challenge to discrimination based on disability.

### ***Social Model of Disability***

In response to a history of medicalization and the momentum created by the Disability Rights Movement, Oliver (1990) introduced the Social Model of Disability, which challenges the

view of disabled people as passive recipients, seen through a lens of a “personal tragedy theory of disability” (p. 1). Instead, the Social Model of Disability places responsibility for social change on society, policies and the overall environment which have created and perpetuated the idea of disability. In this view, society is seen as maintaining the notion that disabled people, in order to be fully functioning and engaged citizens of their society, must be alleviated of their impairment and thus become more like a ‘typical’ (read: non-disabled) individual. As shared by Oliver (1990) in a defense of the use of identity-first over person-first language, “[D]isability is an essential part of the self. In this view it is nonsensical to talk about the person and the disability separately and consequently disabled people are demanding acceptance as they are, as disabled people” (p. xiii). The Social Model of Disability not only challenges the dominant medical view of society, but simultaneously advocates for the existence and affirmation of a ‘culture’ of disability.

### *Nothing About Us Without Us*

Responding to an increased call for self-determination, the phrase “nothing about us without us” was adopted and is attributed to the Disability Rights Movement. In breaking down elements of oppression experienced by people with disabilities, Charlton (1998) popularly connected the phrase to the Disability Rights Movement and is noted as stating,

Historically, the only choice people with disabilities had in their personal struggle to survive was to individually resist isolation, even death, by relying on others. This meant, practically speaking, begging and becoming dependents of family or charities. That has begun to change. Now there is a movement of empowered people that seeks control of

these necessities for themselves and their community. But this movement faces enormous challenges and choices as well. How these challenges are confronted will inform the effectiveness of the movement itself and its impact on the everyday lives of people with disabilities. These choices have life and death consequences. (p. 165)

In this sense, the Disability Rights Movement can be understood both as a response to the history of social, political and economic exclusion experienced by people with disabilities, as well as a demand for increased participation and leadership in society going forward.

### **International Classification of Functioning, Disability and Health (ICF)**

Released by the World Health Organization (WHO) in 2001, the ICF was an attempt by the global community to provide a standardized way of measuring health and disability in individuals around the world. In this way, statistics on disability and health can be more accurately assessed over time. As described by WHO,

ICF puts the notions of ‘health’ and ‘disability’ in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity. ICF thus ‘mainstreams’ the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability. (World Health Organization, 2002, p. 3)

The significance of the ICF seemingly lies in its acknowledgment of the Disability Rights Movement and in its definition of what it means to be healthy. The WHO (2002) highlighted the

importance of “improving performance by modifying features of the social and physical environment” (p. 5) as well as acknowledging the internal medical needs of the individual. Combined, the ICF is described as fitting into a “biopsychosocial model” (p. 9) (WHO, 2002). Emphasizing the idea of universality, health, as measured by the ICF, is a continuum where every person has a place, regardless of the existence of a diagnosed disability. In other words, we all experience varying levels of functioning, some benefitting from more supports and some requiring less.

### ***Limitations of ICF***

The ICF model, however, has its limitations in terms of being integrated into a critical theoretical framework. While it does intentionally move away from a medicalized model and attempts to blend with a Social Model of Disability, it nevertheless relies on a positivist view of health whereby professionals who have researched and created the ICF model, disseminate specialist knowledge to other professionals who then measure an individual in order to compare them to a national or international average. This understanding of health and disability fits into a biopsychosocial model which emphasizes a multi-layered understanding of what constitutes and impacts the health of an individual; however, while this is a significant step towards a critical understanding of disability in terms of its movement away from a purely deficit model, it deemphasizes a structural understanding of disability, and neglects to highlight self-determination. Further, in regards to its relationship to critical theory, it may not go far enough in critiquing the larger structure that govern definitions of disability and health.

## **Neurodiversity Movement**

In line with WHO's contention that rather than being described as healthy or disabled, humans can be seen as existing on a spectrum of health, neurodiversity offers a similar position. Neurodiversity conveys that in relation to the vast differences humans display in neurocognitive functioning, those who display 'typical' cognition are not excluded from the full spectrum of neurodiversity, but rather are a part of this diverse continuum, as 'neurotypical' (Murray, 2019).

The Neurodiversity Movement is a response to the historical exclusion of neurodivergent people in all aspects of society. In substantive areas that are institutional such as government policy development, or grassroots such as community development, the perspective tends to be dominantly neurotypical, often infantilizing and disparaging people who are neurodivergent (Hughes, 2016). A history of oppression has served to "reinforce stigma around disability and often misrepresent the experience of neurodivergence" (Hughes, 2016, p. 3-4). This misrepresentation and exclusion by the dominant society led to the mobilization of the Neurodiversity Movement situated within the Disability Rights Movement.

Connecting this concept into critical theory, neurodiversity as a movement can be understood as resisting the historically dominant discourse of what it means to be 'normal' or 'typical' in society. Rather than viewing neurocognition as a hierarchy, with neurotypical people inherently placed at the top and neurodivergent people being placed under them, neurodivergence aims to re-structure this understanding and view cognition through a critical lens. To be neurodivergent in this perspective means to be emancipated from the dichotomy of normal versus abnormal. Emancipation from dominant ways of knowing is one of the aims of



critical theory, described by Moosa-Mitha (2015) as possessing the “conscious goal of producing emancipatory social change” (p. 72).

Despite the seemingly united approach from the disabled community to the neurodiversity movement, Hughes (2016) highlights the complexities of oppression and the multiple directions in which it can operate. Created and largely led by the autistic community, neurodiversity serves not only as a response to oppression experienced from the direction of dominant society, but also from the exclusion of the larger Disability Rights Movement which has been criticized for its tendency to exclude people who are neurodivergent and/or have intellectual disabilities (Hughes, 2016). In further analyzing these multiple layers of oppression, the Neurodiversity Movement has also been criticized for a tendency to exclude people with intellectual and cognitive disabilities, often those who are non-verbal or minimally verbal (Hughes, 2016). This is an example of how power and oppression may manifest in unexpected and perhaps unintended ways, with the formerly oppressed seeking to make change and, in the process, opening up the possibility of excluding others.

### **Critical Disability Theory**

From the culmination and continued discourse on disability rights through the lens of critical theory, a relatively postmodern development has entailed the emergence of Critical Disability Theory. Moving beyond a historically social versus medical model, critical disability studies combine what has come before in the Disability Rights Movement with postmodern “feminism, queer and post-colonial studies” (Goodley, 2013, p. 632), along with an intentional realization that exclusion and oppression of disabled people is a social construct created by

ingrained, dominant, capitalist ideologies that have impacted the relationship between the ‘abled’ and the ‘disabled’ (Goodley, 2013). This social construct, as much as it is ingrained, can be accepted and utilized within a relationship, or it can be intentionally *not* utilized, thereby superseding or dismissing the entire construct. Foucault (1982/2000) brings this idea into a wider context relating to power relationships:

The exercise of power is not simply a relationship between “partners,” individual or collective; it is a way in which some act on others. Which is to say, of course, that there is no such entity as power, with or without a capital letter; global, massive, or diffused; concentrated or distributed. Power exists only as exercised by some on others, only when it is put into action, even though, of course, it is inscribed in a field of sparse available possibilities underpinned by permanent structures. (p. 340)

In this sense, power is a construct of the human mind, and arguably can be turned on or off, used intentionally or not used, thus providing the opportunity for emancipatory practice. Extended further, this thesis builds on the premise and guiding orientation that the power relationship between abled and disabled individuals, institutions and societies are socially constructed and only exist when implemented.

### ***Intersectionality***

A key element of critical disability theory is the intentional engagement of intersectionality. In her pioneering work, Crenshaw (1989), in relation to the experience of sex and race, identified that “the intersectional experience is greater than the sum” (p. 140). Similarly, a critical lens on ableism reveals that disability, perhaps due to its socially constructed

and socially defined origin, interacts with the notion of the Other, which is shared by the experiences of women, people of colour, racialized communities, Indigenous people, people in the LGBTQ2S+ community, people in poverty, and identities within each of these groups that find themselves multiply marginalized. Goodley (2013) outlines work that has intentionally crossed disability studies with other identity groups, thus resulting in a more layered, complex understanding of intersecting identities.

**Crip Theory.** In crossing paths between queer studies and disability studies, ‘crip’ theory challenges the notion that dominant definitions of normalcy (e.g. heteronormative, able-bodied, male/female) are to be accepted unconditionally and by default (Goodley, 2013). As a form of critical theory, crip theory goes further to emancipate itself from limited understanding by reclaiming the derogatory (as it has been understood) term: crip (Annamma et al., 2013). Adding a further critical element, a “normatively understood” (Goodley, 2013, p. 638) disabled or queer body can be ‘cripped’ by redefining the normalized view of that body from a stance of self-determination, thus “recasting it as a place of possibility” (Goodley, 2013, p. 638). Goodley (2011) also describes how crippling can occur in the direction of the dominant body, exemplified as how “masculine bodies can be queered (re-wired) by the experience of disability and impairment” (p. 158).

**DisCrit Theory.** Another example of critical disability discourse that attempts to understand the complex intersection of identity and multiple marginalization is ‘dis/ability critical race studies,’ also known as DisCrit (Annamma et al., 2013). The provocative ‘/’ in ‘dis/ability’ is intentionally used in DisCrit as a way to “disrupt misleading understandings of

disability, as it simultaneously conveys the mixture of ability and disability” (Annamma et al., 2013, p. 24). This can be seen as collaborating with crip theory in its use of re-evaluating and re-signifying the use and power of linguistics.

Similar to the challenges with identity discussed in crip theory, DisCrit likewise confronts the socially constructed, and historically white supremacist definitions of what it means to be a person of colour and/or dis/abled (Annamma et al., 2013). These definitions of what it means to either be part of dominant culture or to be ‘Othered’ are human categorizations and hierarchies that historically have been ascribed dominance by societal structures and institutions, and thus have prescribed this difference as a deficit on the part of the Other (Annamma et al., 2013, p. 12). DisCrit views dis/abilities as “*not ‘given’ or ‘real’ on their own*” (emphasis in original) (Annamma et al., 2013, p. 3), but rather as reliant on the perpetuation of unquestioned dominant perspective, and the “shifting boundary between normal and abnormal, between ability and disability” (p. 10).

**Critical Intersections.** While critical disability, crip, and DisCrit theory, can be seen as trying to emphasize disability, queerness, and race, respectively, the aim is not to highlight one experience of being oppressed over the other. Rather, it is meant to underline how these identities, “have been used in tandem to justify limiting access” (Annamma et al., 2013, p. 20).

As Annamma et al. (2013) explain, “DisCrit rejects any attempt to offer an account of the life and experience of all people with dis/abilities without their voices” (p. 21). As was previously touched on in the potential limitations of the Neurodiversity Movement, this reliance on a self-determined participation by a marginalized group, runs into challenges when it comes

to intellectual and cognitive disabilities, largely manifested by non-verbal and minimally-verbal individuals. If their ‘voices’ (perspectives) were involved in DisCrit discourse, certain questions or issues would arise, such as: what would that involvement look like, and would it match the values and tenets of those already involved in DisCrit discourse; and if they are not currently reflected, what/who is missing in critical disability representation. These are potentially significant questions to consider in future work between and within critical disability theories.

An example of the socially constructed nature of dis/ability is the Diagnostic and Statistical Manual’s (DSM) definition of autism spectrum disorder (ASD) which, over the course of its development and the evolution of the Manual, has undergone changes in defining who is and who is not autistic. Inconsistency and the idiosyncratic nature of this definition is further noted by the socio-historic process of the DSM, which has been criticized for its lack of process transparency and alleged connection to special interests such as the pharmaceutical industry (Kamens, 2010). In the sense that this information is arguably not publicized or situated within an orientation to diversity, such an example serves to highlight one of the goals of DisCrit, and perhaps touches more generally on the aims of crip theory and critical disability theory: “to unmask and expose the normalizing processes of racism and ableism as they circulate in society” (Annamma et al., 2013, p. 7). Specifically to autism research, Cascio, Weiss and Racine (2020a) argue the importance of engaging in the work of intersectionality; they describe, “Reflecting on these issues can help researchers plan and conduct studies involving participants on the autism spectrum ethically and meaningfully” (p. 3).

## **Limitations**

As a thesis informed by, and allegiant to, a critical theoretical framework, but operating within traditional academy-based guidelines, this project must be seen as limited in its ability to disassociate itself from the tenets of these structures. Despite the post-structural nature of critical theory, this research project, being one that involves data collection from humans, was required to pass through a formal, institutional, ethical review and approval process before it could occur. Further, as part of the traditional way of testing knowledge at a masters level, a thesis defense will be conducted where I will follow formality and be questioned by a committee of people considered experts in their respective areas. While I do not question their experience, knowledge and contributions to social work and research, I do feel uneasy claiming a purely critical framework while simultaneously adjusting my project in order for its fit within institutional expectations of a masters level thesis. On the other hand, education invites critical reflection on convention and social reality, often creating space for critical ideas and discussions to be worked through and explored. Cannella and Lincoln (2018) highlight this potential tension or dilemma when they describe the institutional tradition:

Traditional social science tends to address research ethics as following particular methodological rules in practices that are designed in advance and would reveal universalist results identified as ethical from within an imperative that would generalize to “save” humankind. For criticalists, however, this “will to save” is an imperialist imperative. Rather, critical radical ethics is relational and collaborative; it aligns with resistance and marginality. (p. 84)

Reflecting on these considerations, this thesis is premised on a critical reflexive stance in order to, as much as possible, critically reflect on: when, where and how positivist approaches are inevitably occurring in the research process.

The depth and breadth of critical theory is as much its reason for engagement herein, as is its challenge to incorporate within the confines of a singular study with a practical approach. While not intending to go into rich depth for each of these theories as presented in this chapter, there are overarching themes that seem to tie these ideas together (i.e. emancipation, reflexivity, structural and positivist critique), which may be helpful in connecting critical theory(ies) into different stages and aspects of this project.

A further limit of this theoretical outline is the reliance and over-representation of Western-biased thoughts/ideas and conventions. For example, it may be realistic to write about the intersection of queer and disability theory in Canada where there is (currently) a federal liberal government in office, but there are approximately 13 countries in the world where identifying with the LGBTQ2S+ community is met with the death penalty (Oliveira et al., 2017), and thus it would be unsafe for individuals to encourage intersectional critical discourse. Further, there are communities within or closer to Canada where people of colour, including black, brown and Indigenous people, would not feel safe asserting their racial identity in relation to disability discourse. Critical theories, as well as the topic of this thesis, must be viewed as a privilege that exists in this particular context and in this particular time, but that may not be generalizable across cultures or countries.

Critical theory, having its roots in 19<sup>th</sup> century Marxist philosophy, is also limited by its ability to be clearly articulated due to its long and constantly shifting history and application. Although it has appeared in different formats over time throughout Western society (i.e. feminism, post-structuralism, critical systems thinking, participatory research, etc.), it becomes more challenging to apply it to practice as it continues to be referenced in new approaches, such as crip theory and DisCrit theory described earlier. Mullaly (2001) identifies this challenge in social work, and in discussing the importance of bridging critical theory into postmodernism, highlights the need to “retain ideals of social justice, emancipation, and equality in a way that respects difference, diversity, and inclusion” (p. 317). Thus, while critical theory can be a challenge when attempting to understand its vast history and roots, there are ways of accessing the foundational elements of the approach, such as discussed by Mullaly (2001).

### **Implications for Thesis**

Critical theory and the intersecting theories within it, provide a valuable yet challenging opportunity to engage in dialogue about the nature of partnerships between autism researchers and individuals in the autistic community. I have attempted to embark on this exploration and dialogue with allegiance to the data emerging from the study, amidst what I hope is, and aspire to be, a personal location of humility and recognition of my role and privilege. Accordingly, I acknowledge my risk for a limited scope of observation and interpretation, and have sought checks and means for calibration (discussed in greater detail in Chapter 4).



### ***Writing Back***

Goodley (2011) describes the exercise of ‘writing back,’ whereby marginalized perspectives are provided creative space to reflect on their experiences from a curious and critical stance. For example, crip and DisCrit theory suggests that knowledge and the means of producing that knowledge, must be re-positioned in disability research in order for productive and ethical research to continue with the autistic community. This exercise of writing back “reclaims the research agenda” (Goodley, 2011, p. 163) and “deconstruct[s] dominant modes of cultural production in ways that give voice to their potentialities” (Goodley, 2011, p. 163).

### ***Profession Allied to the Community (PAC)***

Another helpful and informative concept by Goodley (2011) that has resonance for this thesis is the notion of ‘profession allied to the community’ (PAC). This is described as “services and professionals that respond to and are led by the aspirations of disabled people and their representative organizations” (Goodley, 2011, p. 173). In practice, this would mean professionals being accountable directly to the autistic community, addressing concerns that are of importance to those impacted in the community, including the essential work of researchers in meaningfully collaborating with and between marginalized populations. Such a premise, as central to the design and development of this project, will be further described in the description of study methods.

### **Summary**

As a project meant to examine and potentially challenge traditional notions of research engagement between academics and the autistic community, this research is supported and

scaffolded by a critical theoretical framework. This approach seems appropriate and in line with the thesis topic, evidenced by the nature of critical theory to be (a) wary of imposing positivist research; (b) aware of historical oppression in order to take action towards change; (c) critical of structural underpinnings; (d) conscious of current influences of dominant thinking; (e) supportive of personal choice; (f) informed of the potential for, and possible need for, structural change; and (g) mindful of the nature of these changes to be made through daily acts of liberation and education (Agger, 2006).

From its roots in Marxism, critical theory has developed and evolved through its adoption by the Disability Rights Movement and influence on the transition from a medicalized model to a social understanding of disability (Oliver, 1990). The Neurodiversity Movement, critical disability studies, crip (queer and disability) and DisCrit (race and disability) theories have continued the evolution of critical theory.

This expansive, evolving framework provided the guidance and structure necessary to follow a critical, anti-oppressive process and inform this research. Although there is a wide breadth of content, the key critical tenets - reflexivity, emancipatory approaches, positivist critique, and structural resistance – guided this research.

## Chapter 4: Methods

### Design

This research utilized an exploratory design to address the aims of the study. A flexible, exploratory approach is arguably appropriate for the research aims and research questions, given the lack of research to date that intentionally elicits and engages the perspectives of the autistic community in the questions under study herein. An open discussion between researchers and autistic people, as emerged within this exploratory design, opened opportunity to explore challenges and strengths within research relationships, as well as beginning a conversation towards stronger, and increasingly allied, approaches in autism research.

The study was guided by principles of participatory research (PR), and data analysis was informed by a thematic analysis approach, both of which are further described below. In the spirit of the research topic, it seemed critically important that this project not only report and discuss the potential significance of the research, but also authentically integrate and engage in *allied* approaches as a key piece of the research itself. Thus, elements of PR played a key role in promoting collaborative practices, including self-advocates being directly involved in research processes, and myself actively engaging and seeking to create a ‘welcoming space’ for the community in research leadership (Nicolaidis et al., 2011). These principles and aims were integrated in the study by collaborating and engaging with self-advocates relative to study procedures, including knowledge mobilization, integratively engaging with autism researchers in focus group discussions, and collaborating with both of these groups in regards to future work together in autism research.

### ***Participatory Research (PR)***

Elements of PR were used throughout all phases of this research. PR can broadly be understood to place an importance on “participation and action” (SAGE, 2021) while encompassing various iterations and evolutions, including Community Based Participatory Research (CBPR), Participatory Action Research (PAR) and emancipatory research. This thesis does not attempt to follow any specific PR frameworks, but rather draw broadly from aspects of these approaches, including the meaningful inclusion of autistic individuals in the phases of research, as focused on by CBPR, and the incorporation of community-based actions that result from the research itself, as focused on by PAR.

### **Recruitment**

Recruitment took place among two groups: autistic adults and autism researchers. Regarding autistic participants, recruitment included adults on the autism spectrum who had past involvement in research participation and/or an interest in research. These participants self-identified as autistic, which is consistent with recent convention in PR which typically does not require a formal diagnosis of autistic community members in order to be eligible for participation as an autistic person (Weksler-Derri et al., 2019; Nicolaidis et al., 2019) – in part, important as some adults do not have a formal diagnosis. The researcher participants were academic researchers or student researchers who are involved in autism research projects.

Convenience sampling was used to recruit participants. Autistic individuals had directly been involved in past autism-related research where I was employed as a research assistant or had met me through past study participation or community projects. Several individuals had

already informally expressed interest in being involved in future activities and projects. This is arguably aligned with elements of PR, where intentional discussion with autistic individuals is what can determine the formation of the research question. Recruitment also took place through study advertisement and an invitation in Autism Edmonton publications, Glenrose Rehabilitation Hospital-based forums (e.g., Autism Research Centre), and the Vocational Activities Innovation Lab, University of Calgary (Central and Northern Alberta Region, Edmonton) (See recruitment poster in Appendix A). The researcher participants likewise had an existing working relationship with myself and/or my thesis supervisor. Considering these pre-existing personal/professional relationships, I was intentional (and ethically obligated) to not exert pressure for any participant to engage in the study. This was accomplished with a careful process of informed engagement and consent which clearly articulated participation as absolutely voluntary whereby involvement or non-involvement did not in any way implicate any current or future work being/to be done together (See recruitment email in Appendix B).

## **Sample**

Twelve participants were recruited in total, comprising three small focus groups; each group having a mix of autistic individuals and autism researchers, and one email-based interview. Of the twelve participants, six identified as self-advocates, four identified as researchers, and two identified as both a self-advocate and researcher. Ten participants identified as female, and two identified as male. The ages of participants ranged from 23-61 years, with an average age of 44.9 years. The average age of autistic self-advocates was 46.3 years, and the average age of researchers was 45.6 years. Culturally, seven participants

identified as being Canadian or Caucasian/white, three participants identified as being of European background, and two participants identified as part Canadian and part Asian or European. A range of education levels were represented across groups: one participant had received a doctorate degree; five had a master degree (of the four there was one participant who identified a profession degree in a health discipline); two had a college/non-university certificate or diploma; one had a university certificate or diploma; one participant had a bachelor's degree; one participant had a trades certificate; and one participant had not completed high school.

In regards to the length of time that autistic participants identified as self-advocates, of the eight autistic participants (including the two participants who identified as both a self-advocate and researcher), five identified as self-advocates for four years or less, one identified as being a self-advocate since their diagnosis (21 years). For researchers and student researchers, there was a range of autism research experience from three to 23 years.

### **Data Collection**

A focus group format was used, based on methodologic tenets as discussed by Liamputtong (2011), including ensuring (a) meeting together with content that is relevant and specific to the group, (b) fostering interaction between group members, (c) ensuring a safe and welcoming space for the conversation, and (d) honouring the participants' time and expertise being brought to the group. One individual opted to reply to research questions by email. As well, after initial thematic analysis had taken place, all participants received a follow-up email with a summary of key themes that had emerged from the focus groups, inviting them to comment on the initial themes and to contribute any additional thoughts.

### *Focus Groups/Email Interview*

The three mixed focus groups, as noted above, included autistic adults and autism researchers to integrate sharing together. I intentionally sought to create an environment of equality across groups by facilitating equity and informal conversation between group members, encouraging random seating, and sharing food and beverages informally before the focus group began, and particularly noting that everyone's input was valued. In seeking equitable engagement despite what might be more deference to researchers by autistic participants due to power differentials, more opportunity to express their perspectives was generally given to autistic self-advocates compared to researchers.

Individual interviews were also offered as a participation possibility to honour participant preference and/or availability; however, only one participant expressed interest in a non-focus group format, opting for e-mail-focused input rather than an in-person interview. Holding three focus groups allowed for increased opportunities for discussion by each individual in the groups, and offered greater scheduling flexibility for participants to attend. All participants had verbal capacity to respond to focus group questions; however, based on participant comfort and communicative needs, augmentative and or other means of communication were an option. Data collection occurred before the COVID-19 pandemic; hence, meeting in-person occurred without social distancing restrictions.

Each focus group was audio recorded to ensure accuracy of data for subsequent transcription and analysis. A description of the project was provided before each focus group convened, with written and informed consent being obtained upon meeting. Questions, in

writing, were provided to participants before their attendance at the focus group (i.e., with the email confirmation of the focus group). Participants were invited to reflect on the questions in preparation for the focus group, and note if anything was missing and/or suggestions for changes (See Appendix C for focus group interview guide). Before beginning, focus group members had the opportunity to share any changes they wanted in the interview guide.

Focus groups were approximately 1.5 hours in length, and took place at a local autism advocacy organization (Autism Edmonton) which had staff available to connect with, if needed, for support or referral, if participants experienced distress and needed help. No participants identified the need for this support.

Focus groups addressed the pre-determined questions, but allowed for open discussion that broadly followed the focus group guide. As the focus group facilitator, I attended to group process, sought to ensure engagement by all, and invited participant reflection on focus group questions.

### **Data Analysis**

Following the transcription of focus group discussion and interviews by an experienced transcriptionist, data analysis was conducted by myself and was managed using NVivo software, leading to the identification of codes, categories and themes addressing the research question. Thematic analysis followed the analytic process outlined by Braun et al. (2015) in their work on interview data from health and well-being research. This process included the use of line-by-line coding, categorizing codes, and aggregation of codes in identifying themes (Braun & Clarke, 2012).



Specifically, after categorizing codes and identifying themes, these codes were reviewed to better understand the ‘fit’ of themes within the research topic and to review the compilation of ideas relating to the research question. Data from autistic individuals were analyzed separately from researchers, which were then contrasted and combined to identify areas of difference and synergy. This analysis led to the formulation of themes, which arguably sufficiently offered saturation and addressed the research questions.

Trustworthiness of the findings reflected consensus in coding/categorization, member checking through follow-up with participants (see below), peer debriefing with my supervisor, and follow up with others in the field relative to the resonance of findings. Data confirmability was ensured through reference to written notes during the focus groups and notes kept during the analysis process. Consultation took place with my supervisor and participants throughout the data analysis process. Also, reference adequacy is reflected in the reporting of the research.

### **Member Checking and Follow-up**

Once initial themes had been identified through the analysis process described above, a follow-up e-mail was sent to each participant (see Appendix D). This e-mail invited each participant individually to reflect on how the focus groups went overall, their thoughts on the emerging themes, if there was anything they would like to add, remove or change, and what they would like to see happen next with the information gathered. This follow-up email was intended as a form of ‘member checking’ in order to confirm emergent themes with participants, and seek participant feedback about the research process (Birt et al., 2016; Buchbinder, 2010). Through engagement in the e-mail, participants were provided an opportunity for retrospective reflection

and engagement in an aspect of the analysis process (i.e., validation of themes). The format of an individual e-mail was chosen to ensure that there was an opportunity for participants to express their individual thoughts and considerations fully in a reflective writing context, without feeling pressured by the larger group.

### **Ethics**

This study was reviewed and approved by the University of Calgary Conjoint Faculties Research Ethics Committee. Informed consent was received prior to engagement in the study, and participant confidentiality was ensured from myself as the researcher. Groups were asked to similarly uphold the same commitment to confidentiality.

### **Summary**

The exploratory and participatory nature of the methods used in this study provided an opportunity for fulsome discussions to take place regarding allied approaches to partnership in research. Thematic analysis allowed for an in-depth reflection on focus group discussions, which is outlined in Chapter 5.

## **Chapter 5: Results**

In describing their experiences related to involvement in research, participants offered a rich depth of understanding in regards to what they perceived to be important in ensuring a meaningful relationship between researchers and autistic individuals. The themes that emerged from this discussion are outlined in this chapter. They reflected elements of relational development/engagement along temporal and incremental stages of the research process, including (a) Pre-research and inquiry, (b) Beginning of research, (c) Throughout the research, and (d) Conclusion of research. Themes are presented within each of these stages, although it seems important to recognize that these emergent ‘stages’ entailed continuity and engagement across the research process rather than occurring strictly in distinct or discrete temporal segments. Below is a description of themes as they unfolded along with corroborating text quotes from focus groups, followed by a further discussion of these findings in Chapter 6.

### **I. Pre-research and Inquiry**

A number of considerations were shared that highlight what participants felt are important steps in establishing and strengthening relationships for conducting autism research. These elements were temporally noted as needed prior to beginning a research project (i.e., prior to any major decisions made about the direction of a study). Elements are “a way in” and “research training”, as well as issues to consider and potentially mitigate in this process comprising, “funding issues and inequities in authentic partnership”, “challenges in larger samples and experimental research” and “grant restrictions”. Each of these areas are explained below.

### *A Way In*

In reference to the challenge of knowing how to develop, and then developing, meaningful partnerships or allyship in research, a researcher shared, “because it’s relatively new, it’s not quite clear where you get that education.” A need was expressed for a route into this kind of relationship-building, with one researcher sharing, “I wouldn’t want to force people to interact with me because...I don’t want to invade a space.” In contrast to the researcher perspective, autistic participants shared that researchers need to connect directly with the autistic community as well as groups composed of and led by autistic people in order to let them into the research space. This connection was described as a logical way to learn about allyship and ways to achieve increased partnership in research.

Participants identified concern that too much emphasis on parent perspectives can undermine the autonomy of autistic adults themselves. An autistic individual shared, “parents... can be limited in their field of vision, too focused on their kids. They’re trying to do their best, but sometimes they are off track.” Accordingly, the need for more focus on engaging with self-advocates was highlighted.

To that end, a researcher shared their understanding of ‘community’, recommending that researchers take the necessary time to understand the difference between connecting with the *autistic* community (i.e., autistic individuals) and connecting with the *autism* community, which may include parents, autism organizations and others related to, or otherwise associated with, autistic people.

### ***Research Training***

Reflecting on the role of post-secondary education in potentially supporting emerging autism researchers to develop their skills as community-minded practitioners and scholars who engage with the autistic community, the need for training and mentorship was identified as a key element in advancing research with autistic people. A student researcher observed,

I don't think there's a lot of space for conversations to happen...and so you move on into the world of research...and you haven't really had opportunity to discuss...unless you're fortunate enough to have supervisors that that's where they're coming from too with their [supervisor's] way of thinking. But a lot of people, that's not something that's stressed, to find ways that are going to promote partnerships, allyships and authenticity, you know?

A challenge for student/junior researchers in gaining experience and guidance in participatory approaches was identified to further reflect a general lack of clarity in terms of where to find learning and opportunity to implement/practice partnership/allyship in research. Building this resource in training and research expectations was advocated, as a precursor to ultimately building researcher capacity and aptitude in this endeavour.

### ***Funding Issues and Inequities in Authentic Partnership***

While fair compensation for self-advocates engaged in the research process was valued and viewed as elemental to authentic allied research, challenges in providing such compensation particularly at an early inquiry stage of research development were noted. These challenges highlighted differences between researchers who are often supported by a salary, and autistic

participants who often lack a salary and may rely on income supports. Of further difference, junior researchers at an early stage of their research career often do not have substantial research funding; hence, they may lack funds to support self-advocates involved in their research processes, and certainly at points of engagement before grant funding is obtained. A researcher shared such a concern:

I think that research funders generally are becoming more open to supporting the roles of co-researchers but the truth is that, you know, a truly authentic partnership might start from the very beginning of generating the idea so, of course, when you're just starting out, thinking about what you want to do and writing it up, you don't have a grant so how do you support someone's time at that point.

In contrast to this difficulty accessing funding for compensation at early planning stages of the research, a researcher shared an example of funders requiring plans for 'patient-oriented research' to be reflected in grant proposals, thus ensuring that engagement with the community is planned ahead of time. While this does promote intentional collaboration by researchers, it also speaks to the challenge of encouraging collaboration before getting to this grant application stage as the implication of this funding is that the ascribed financial compensation to participants is supported by the grant *only after* the grant is obtained.

### ***Challenges in Larger Samples and Experimental Research***

A researcher shared their concern that the requisite of a large number of participants such as is commonly found in experimental or other larger studies (and less common in qualitative research) creates a barrier for meaningful engagement or collaboration between the researcher

and research participants as a result of financial cost and practicality (i.e., the high number of participants). As an example, remuneration to participants presents a financial challenge, they argued. It was thought that meaningful engagement implies fair compensation; however, the large number of people meaningfully engaged in these types of research studies was thought to potentially be financially difficult to sustain without significantly more grant support, and logistically difficult to manage.

### ***Grant Restrictions***

Both researcher and autistic participants noted challenges that can emerge when research grants are developed before relationships have been formed, which in turn can restrict the potential for partnership and allyship later on. A researcher spoke about what he viewed as a “research culture” that can exist around grant proposals, implying that there is an inherent pattern or “formula” that is often followed whereby a researcher develops and submits a proposal, obtains a grant, and then recruits participants. An autistic participant reflected on the impact of this perceived research culture and process:

You’re missing the real person, the real equation. For every grant, for every mathematical equation, there is a person behind that, a person that has feelings, a person that bleeds just as much as you do. But the real reality is, we’re nothing more than a thesis.

A student researcher also reflected on this pattern that grant-based research may create and shared that, “there needs to be more time to learn... I think what’s challenging sometimes is when you’re doing research in academia, you’ve got to get a grant, you’ve got to fill all these

commitments, but at the same point you're like, 'I want to be able to work with communities and learn from them'." Accordingly, the structures of academia and grant acquisition via a competitive and traditional approach, were seen as limiting more inclusive processes. While PR may invite such engagement, other research traditions were seen to limit the inclusion of autistic people as participants *and* active agents in the research process.

In the face of restrictive structures, both researcher and autistic participants identified the need for researchers to be critically reflective regarding *how* they are collaborating, but also *why* they have decided to partner and ally with the autistic community. A participant shared,

I think you have to be prepared if you're doing research...you're looking at yourself, like where you are, how are you approaching research, like what are the implications... it has to be a very thoughtful process and sometimes in academic systems things can become almost rushed in a way. You get into the midst of just doing it, but you don't take that time to step back.

Participants identified the need for researchers to ensure intentionality and be clear about their goals related to a given study prior to seeking to collaborate and create partnerships. Clarity was emphasized "to the point where you can actually write it down or speak to it [goals related to inclusion of autistic people and their roles therein]." The importance of re-visiting and re-evaluating group goals was also emphasized as a strategy for a strong partnership, and entailed relational accountability in not just imposing views on the goals of the researcher but also those of the autistic community in the research endeavour.



## **II. Beginning of Research**

In addition to collaboration, relationship-building and researcher training that have the potential to take place early in the research process, participants identified the importance of examining an individual's values related to the research process and team. This included subsequent expectations and persuasions, as well as roles of, and compensation to, all parties in the research. Relationally-imbued notions and values such as authenticity, pushing against tokenism, and fair remuneration, were presented as important, as discussed below.

### ***Authenticity***

Focus group discussions explored notions of 'authentic engagement' and what that means in research. Several key elements were consistently shared across groups, including the notion of being "truthful," "honest" and "reliable." Participants described the importance of being "truthful and honest" and open about the intentions and goals of the researcher, as well as being "reliable" in terms of timeliness and communication. One autistic participant shared an example of a past experience in which they participated in a study, but did not hear back about further engagement despite being told they would. After emailing the research team multiple times, they eventually were contacted; however, a year had elapsed since first participating and it would be an additional year before being meaningfully re-engaged to hear about the results of the study.

Participants stated that authenticity may be viewed differently depending on who is defining it, and whether it is reflective of their values, personal life experience and view of research and community engagement. This variable understanding of authenticity led to a

researcher sharing, “we wouldn’t just assume that there is this definition that we all know. Let’s actually create space to talk about how we’re going to do authentic partnership or allyship.”

As part of what participants conveyed as authenticity and relational accountability entailed in partnership and allyship in autism research, researchers were called on to “remove the red tape and the barriers. You want something, be more real with us and we’ll be real with you.” In this regard, communication barriers in research were referenced such as having only one method of communication to share experiences, and not providing the option of electronic communication as a substitute for an in-person conversation.

Broader communication accommodations were seen as critical to not only including autistic people (and others) in discussions, but also building relationship and mutual trust. These considerations reflected a recognition of various routes towards inclusive community for autistic people and accordingly, challenges when only a singular communication approach is permitted. Allyship was thought to require opening opportunities for communication in ways that are appropriate and easier for individuals with various communication needs and preferences.

Researcher and autistic participants discussed how these kinds of group conversations (i.e., such as the focus groups for this thesis project) may be what are needed in other studies, although other approaches also may be needed (e.g., online engagement as was exemplified by one participant’s communicative preference in this study). Taking the time to create conducive spaces to examine the meaning of, and means to achieve, ‘authentic engagement’ in action, were seen as relevant, useful and important processes. Some participants suggested that this should be a regular practice for research teams early in their work together. As such, participants sought

opportunity whereby researchers and participants can speak or otherwise engage openly and truthfully which, as a consequence, becomes an authentic process. Reflecting on what is needed for such a process, a participant described, “maybe these kinds of conversations, like actually sitting down between researchers and self-advocates and whoever else we think needs to be at the table and talking about what this looks like, in a way at a grassroots level.” Relatedly, ‘transparency’ was shared as an important value in allyship between researchers and autistic participants, which was described to potentially be nurtured by open and honest conversations in the research process.

**Pushing Against Tokenism.** A researcher reflected on past research experience whereby deadlines and productivity pressures led them to face inherent conflicts and challenges in seeking the ‘authentic’ partnership they were attempting. They shared,

I’m guilty of this too... We’ll put people’s names on our team and then sort of just go ahead and do the research, often without even being really collaborative with people...I think especially when you’re engaging people with lived experience...something has to be set out so it’s not tokenistic representation.

This tension was also represented by an autistic participant who shared, “I think the researcher has to genuinely see the value so that they’re not doing it just ‘cause you’re supposed to do it.” Approaches to resist tokenistic engagement were described to include fair compensation, as described below.

### *Fair Compensation*

Connected to the values of authenticity and transparency, focus group participants communicated the need to clearly articulate roles and expectations at the beginning of a research project, including expectations for, and clarity regarding, compensation. Fair monetary compensation to participants and research team members was discussed, with participants especially noting the difference in power between a researcher who receives a salary, and a voluntary participant who often does not. While monetary compensation was an important element to consider in the notion of allyship, compensation was also discussed more holistically regarding what autistic individuals may additionally view as valued compensation. A participant shared,

There's also the question of sustainability, like what skills will they get from this project that can help them to get other jobs because in reality, research projects are short-lived right?...And you know when you have medical bills and other bills to consider, like even the basic needs, there needs to be a way to create some sense of sustainability...[that] improves your position for whatever you're trying to achieve. Yeah, and as an advocate, they could propose to assist the community.

Other ideas on how participants and the larger autistic community could be compensated were shared, including the idea of an internship. One autistic participant suggested that the research community needs to “find a new way to include internship in a research project—an adapted internship into a research project for autistic people that would give them a different [or] new access to research fields.” The idea of “reciprocity” was discussed, acknowledging that the

researcher benefits from research in terms of academic and career advancement, while the participant often will receive minimal compensation. To encourage reciprocity, it was suggested that at times it may be appropriate to offer participants paid employment through their participation in the research, thereby providing work experience, compensation and bolstering of one's resume and reference base for potential future employment. In addition to re-imagining compensation as something larger or more substantial than cash or gift-cards, participants noted medical needs, prescription compensation, and services that would benefit their quality of life overall as consideration in payment structures for autistic people in research.

While fair compensation was discussed as a key area that continues to require refinement and development by the research community (e.g., insertion as a line item in grant budgets), a researcher reflected on an experience with a grant review panel which demonstrates change and growth in this area. They described a helpful commitment of the grant holder who asserted: “you’re not paying your community members enough to respect their contribution. You need to take money out of your budget somewhere because you need to pay more money there.”

### **III. Throughout the Project**

Participants provided a range of instructive considerations related to allyship and collaboration *during* a research project. The considerations were described as integral to truly engaged allyship, and included intentionally attending to group dynamics between the research team and participants, proactively addressing power relationships between individuals in the group, bringing one's *authentic self* to the group, and considering deeply the role of personal relationships. Each of these elements are addressed below.

### *Working Together: Group Dynamics*

Some autistic participants, all of whom were verbal and without intellectual challenges, expressed concern regarding past experiences in which they were placed in group settings with other autistic individuals who were minimally verbal and/or perceived to have substantially less cognitive capacity. A participant shared, “they have their own form of ability, but their [ability is] not equal to my own.” There was a concern raised about “masking,” whereby the individual described having to “downplay” their individual contributions to a group conversation (i.e., contribute less complex thoughts and ideas) in order to fit in with autistic colleagues in the group.

Researchers identified challenges ensuring inclusive group dynamics that nurture a positive and productive research process, relative to group-based/interpersonal data elicitation. Reflecting on their research experiences, a researcher shared, “In fairness, you know, . . . that’s not totally foreign to me as a researcher because there are some of my colleagues that may be brilliant researchers, but they also have their own interpersonal styles.” In response to the challenge faced by autistic participants regarding the need to engage and work alongside other autistic people who communicate at a similar level, a researcher shared, “I mean it’s an interesting issue because you work with people on research teams partly because you get along and partly because of that friendship, but also because of what they actually contribute to the research, right?” The agreement here between researcher and autistic participants implied that if a research ‘team’ is to work together well (i.e., as an authentic and productive working partnership between autistic individuals and researchers), there needs to be a minimum level of

cognitive capacity and shared interactivity among participants, thus risking the potential exclusion of the full spectrum of autistic people, given substantial communication and cognitive differences among the autistic community.

Besides these questions regarding the engagement of autistic individuals across the broad autism spectrum, participants conveyed the need for “chemistry” between group members and what factors actually contribute to overall good group work and collaboration. One self-advocate described “working well together” as “people...doing the things that they’re passionate and really good at...It’s not like everyone has the same roles.” Similarly, a researcher discussed “what it might look like if it’s working well” which included the work being “mutually beneficial and each person contributing.” They also expanded on this challenge saying, “but I’m actually not sure that I know how to identify someone, like...what’s the right chemistry to... lead to that kind of authentic working relationship?”

Establishing clear and transparent expectations for both autistic and researcher study team members – although perhaps somewhat tangential to finding optimal group dynamics – was described as an essential part of forging an authentic and productive research partnership, perhaps leading to deeper conversations about inclusive research team development that is truly engaging of autistic members.

### ***Power Relationships***

Embedded throughout discussions, participants identified the element of ‘power’ in terms of ‘who gets to decide what these conversations are about’; ‘who gets to decide which

individuals are present at the conversations’; and ‘how is it decided which topics receive their due weight in consideration.’

Participants felt that “the research community should be working *for* [the autistic community]...*for* or *with*.” They did not seek for autistic participants to usurp research leadership per se, but rather sought for autistic individuals to be an engaged and active part of that process and practice – engaged and collaborative leadership as authentic practice.

Participants’ understanding differed in terms of how power relationships in research are understood. While one participant did not see the “collecting of information” as necessarily a concern in terms of power imbalance in the research relationship, another participant suggested, “it’s not the collecting of it, it’s what you do with it. And so if the researcher does all of the analysis, then that puts power back into the researcher’s hand.”

### ***“Bringing Yourself”***

Some autistic participants described the importance of bringing, and being welcome to bring, their ‘true selves’ to group/team work, particularly when it is being led by ‘neurotypicals’. Some participants shared their experiences of research participation and group engagement in other areas of their life, where being ‘themselves’ was experienced or communicated as socially unacceptable. Reflecting on the reciprocal exchange between autistic and researcher participants related to the risk of not being able to authentically bring themselves into a research relationship and context, a researcher stated,

So I mean as you said, it wouldn’t be fair to the researcher to expect the person with autism to somehow not be who they are so it’s not about conforming somehow because,



you know, the reality is that they're part of the research team because they're bringing unique perspectives so they should feel comfortable to be who they are and contribute that perspective. At the same time, and this is where I think it gets a bit delicate, like for me, like any other research I work on...I'm working as part of a team and each person kind of comes to the table with a slightly different perspective and skill set.

### ***Personal Relationships***

The existence of various levels or foci of relationships (i.e., personal friendship, community advocacy, working relationships) was viewed as a challenge to the research process. Both autistic and researcher participants recognized that personal relationships could impact the honesty and candor that was earlier described as integral to authentic engagement in research. An autistic participant described their concern that a personal relationship would cause participants to be “scared of offering something that would go against the person speaking.” In this participant’s understanding of allyship, they described, “You’re supporting that person in every way and so if you’re doing that by giving the answers that you think they want to hear, then allyship is perhaps not where you really want to get to from a research perspective.”

Relational depth, however, was described as being a potential benefit to productive research. An autistic participant shared this sentiment, stating, “While it may have a negative impact...there’s also, I think, then space for...creat[ing] something that’s mutually beneficial rather than just benefitting one side.”

Participants identified possibility for individuals to only provide what they *think* the researcher wants, rather than participating honestly and genuinely. Relational strength was

described as a possible mitigating response to this risk; that is, through strengthened and solid relationships between the autistic individual and researcher (and others on the team), with honesty and role clarity conveyed as integral to safety. An autistic participant described, “You have two people who want to please each other and make sure both people are happy. That’s great for the two people, but what about for the actual data.” To such a challenge to the research process, clarity of role was deemed important and feasible, and relational strength, while also important, was viewed to require a careful balance. Concern was raised in terms of dual relationships, mixed focus on the varying relationships on a research team, and potential risk to professional boundaries. One researcher described,

I think that one anxiety that I have is that I would want it to be this kind of respectful, mutually beneficial relationship,...but I would also have to be cautious about making sure that it doesn’t become a therapeutic relationship...One wants to support every member of the research team and one does that in the context of a professional relationship.

Despite these concerns about possible conflation and risk of negative impacts that personal relationships could have on research processes and outcomes, participants felt that personal relationships can create potentially higher quality research (i.e., improved appropriateness and relevance of the research to the community, improved methods of knowledge translation, and accessibility to research findings/outcomes).

#### **IV. Conclusion of the Research and Knowledge Mobilization**

An important topic discussed throughout the focus groups and interview was the link between research participation and the community at large, both in the sense of how the individual participant is connected more broadly, but also how the research project translates to, and is mobilized in, the community. Participants addressed the engagement of the research and the work of the research team, with the ultimate aim of completing the research and sharing findings, including the optimization of end-of-study and post-study impact. Below are the key themes that emerged within this domain. In particular, participants conveyed the need for research and transformative impact in the area of autism research (i.e., an increased emphasis on the development of the researcher-participant relationship, increased accessibility to research findings, and increased collaboration between the autistic and autism research communities). As well, participants shared the importance of concrete ideas for moving forward and finding ways to turn concerns into tangible solutions and proactive action.

##### ***Beyond Research***

Allyship *within* the research context was the focus of discussion; however, both researcher and autistic participants identified the importance and potential impact of partnerships in other spheres of society such as decision making in government, community relations and clinical and community practice. When discussing how researchers could better partner with autistic individuals, a participant shared, “The ways that research could include self-advocates is probably similar to the way that governments could include self-advocates. It starts with us—the

community—and then it goes to other researchers, then it goes to the politicians on the higher level.”

Expanding on research approaches that enshroud allyship as a *way of being*, researcher and autistic participants discussed a tendency for these partnerships to have an overall ‘life’ impact beyond just a given research project. Authentic research participation, in this sense, was described as providing an opportunity for autistic participants to not only contribute to research, but also gain essential tools and potential pathways for effective engagement in group work, leadership and life skills. An autistic participant explained,

That’s something that you really need to work on and find out, be clear to yourself what it is when it comes to a research partnership and engagement. We’re just talking about research partnerships, but it helps in life as well. And that’s something that could emerge [from research participation] like good help over a lifespan or a good start for a young adult to be equipped with those tools, the right reflexes.

A researcher replied in this interaction, adding,

It’s a good point because personally, I feel like if someone on the spectrum was to learn about how to be effective in this kind of role, they should learn not only about what they can contribute but how to make sure that they’re not being taken advantage of.

### ***Beyond Publication***

Regarding the sharing of academic research, recommendations suggested knowledge translation and diffusion beyond publication in academic journals. From an accessibility lens, journal articles were noted to require an academic subscription through a university, unique skills

in navigating academic journals and databases, and often a writing convention that is geared to an academic audience (i.e., with academic and research jargon). Participants noted that despite increasing examples of ‘plain language’ versions of articles being provided, accessibility continues to be a challenge whereby autistic individuals often have difficulty accessing publications once they are released.

A key idea shared regarding the expansion of allyship in research beyond the primary aim of scholarly publication, reflected the notion of having “feet on the ground.” An autistic participant shared, “It shouldn’t be just doing journals or just publications, but it should exist somehow in the community.” This was echoed by a researcher who reflected,

Yes, there’s lots of research going on, but most of it doesn’t get outside of the researcher community, so often people won’t see it. And very little of it is based on identified priorities from the autistic community...So it’s ideas that we’ve come up with and some might be perceived as really important and some might not be...I think in any research, there should be an end goal but also, ‘is it useable in the world once the results come out?’.

## **Moving Forward to Sustained Engagement**

### ***Sharing and Teaching***

Participants strongly advocated for increased collaboration between autism researchers and the autistic community. This desired collaboration was communicated as needing to develop as a result of researchers reaching out to the autistic community, given that researchers currently control much of what happens in the research endeavour.

Increased collaboration in autism research was thought to extend to the processes and outputs/outcomes of the research. An autistic participant stated, “You’ve got the paper and then you’ve got the human. Where do the two come hand-in-hand, when are you going to ask someone like me how we feel about what you just wrote?” This wish for increased and integral information-sharing, and engagement in that process as an outgrowth of allyship, was described to include, for example, a draft of a written article from a study being shared with autistic people with feedback being utilized (as suggested by the participant quoted above). Accordingly, participants sought greater involvement by autistic individuals in the post-study implementation stage such as the ‘end of grant’ knowledge sharing process.

### ***Sustainability***

Recommendations were shared throughout the focus groups that pointed towards a way forward for a higher standard of respectful, mutually beneficial partnership between the autistic community and autism researchers. The following elements of partnership and allyship were shared, with the view that these elements could nurture the infusion of allyship in research: development of researcher-participant relationship, accessibility of research findings, and collaboration of autistic and research communities. Further, participants conveyed the potential benefit of the following, as discussed below:

- A mediation/advisory body that navigated or liaised, as needed, between the autistic and autism research communities,
- A training/orientation and/or mentorship initiative that could provide mentorship and guidance to autistic individuals seeking research information, experience and

engagement opportunities, and support to researchers (experienced or otherwise) in salient areas such as partnering, allying or inclusively engaging with the autistic community

- A resource-sharing partnership with a research or university setting.

Each of these recommendations is briefly described below.

**Mediation/Advisory Group.** The existence of a ‘mediator’ group was thought to potentially serve as a ‘bridge’ between the autistic community and autism researchers. This was described as having the potential to serve as an advisory group which researchers could connect with in order to (a) recruit participants, research assistants and autistic partners, (b) share drafts of articles for feedback and consultation, and (c) access training (e.g., consultation, workshops) on respectfully and collaboratively engaging with the autistic community. Autistic individuals were thought to also likely derive benefit from this group by (a) getting connected to collaborative research studies for participation, employment and/or opportunities for consultation/advisory engagement, (b) increasing awareness and accessibility to research studies, and (c) accessing training and orientation on the ‘rights’ of research participants and other research learnings.

**Training/Orientation.** The need for research training was identified as beneficial and important for autistic individuals, but also for student researchers and other researchers interested in building or enhancing inclusive research approaches. Referring to autistic participants, a researcher shared their concern that participants should be aware of the risks and benefits of research engagement: “so kind of coming into the situation so that they’re prepared and they

have some sense about what is actually reasonable so that they're not getting taken advantage of.”

The concept of an ‘orientation’ was discussed as potentially helpful in preparing a researcher who would like to collaborate with the autistic community, but may not know how to proceed or perhaps lack an understanding about the autistic community. It was suggested that the aforementioned ‘mediator group’ could play a role in this training or orientation, thereby ensuring that both groups (i.e., self-advocates and researchers) were entering into a partnership on a strong, equitable and well-understood foundation.

**University-associated Group.** A participant shared the potential benefit of a group associated with a university within one’s community. One example of this type of partnership was described as the Community University Partnership (CUP) at the University of Alberta in Edmonton, Canada, which is a collaborative partnership between the university and various community agencies and organizations. A potential benefit of this engagement was discussed as increased access to shared resources, physical meeting spaces, and opportunity to engage and work together in important areas of inquiry and advancement.

**Mentorship.** Participants recommended that researchers offer mentorship to autistic individuals who are interested in research, as well as students and junior researchers. This was noted as potentially contributing to the ‘training/orientation’ idea (discussed above) whereby an engaged ‘learner’ could better understand the research process from the researcher’s lens as well as their own roles (e.g., participant, co-researcher, knowledge mobilizer, etc.). This kind of engagement, learning and relationship-building was believed to offer the potential to enhance



knowledge and relationality, and break down barriers and power imbalances that currently favour researchers relative to autistic people/self-advocates and research participants.

Expanding on the idea of a mediator group, autistic individuals who are experienced as researchers or research participants, were thought to have a venue, within this group, for mentoring less experienced autistic participants and researchers. The mediator group was thus viewed as a means or access point for less experienced individuals who are looking to increase their knowledge or participation in autism research, and for those with greater experience to make their knowledge and experience accessible to others. Participants felt that a mediator group could offer opportunity for autistic individuals to mentor student researchers, and researchers overall, who may be less-experienced in collaboration and partnership in research.

### **Member Checking**

Through the ‘Member Checking E-mail’ provided after initial data analysis, participants reflected on their experience in the focus groups, reviewed and critiqued emerging themes, and offered considerations on how this thesis/study should be ‘actioned’ in moving forward. Overall, participants reported being satisfied in their experience within the focus group, with some individuals noting an important and appreciated tone of “respect.” In response to the question of whether their engagement in the focus group reflected principles of allyship, participants reflected positively on the discussion, noting the tenor and focus in the group as nurturing a, “desire for authentic allyship” and a feeling that “receptivity” and “respectful tone and words” had been a characteristic of their experience.

Member checking comments of participants related to the initial list of emerging themes were affirmative in terms of their perceived resonance with participants' reflection of group content and own perspectives. A participant reflected on the challenge of exploring the concept of allyship in a limited-time and single study, sharing conversely that, "allyship is an ongoing process of building relationships and focus groups generally are 'one-point-in-time' conversations." As well, a participant shared their wish that there had been more opportunities for feedback sessions to take place. This seems to imply that further discussion, exploration and application of allyship in research, are desired and warranted.

Regarding the question for next steps of this research and its findings, participants agreed that these focus groups could potentially lead to further discussions and collaborative work. An autistic participant shared, "Challenges exist, but this is a start." A researcher participant expressed their interest in some of the proposed ideas from the focus groups, sharing,

I would love the ability to access an informed advisory group from the autistic community in relation to all research (from early stages) because we seem to seek the same advisors for every project and I sometimes feel like I am burdening my trusted collaborators.

Another participant noted the importance of broadly sharing the learnings from this research in order for it to "live out in the community."

## **Summary**

Participants contributed a wide range of experiences, reflections, creative ideas, recommendations, concerns, questions, and enthusiasm to the topic of allyship between the

autistic community and autism researchers. Across focus groups, both autistic and researcher participants recognized challenges and ways forward that impact each phase of the research process (i.e., before the research begins, when the research is just beginning, throughout the research project, and at the end of the research project), as well as means to integrate proactive and constructive shifts in the research process and ethos, including the development of authentic working relationships within a given research study.

Identified challenges comprise navigating the complex relational aspect of a group of diverse people working together, fair compensation, and the related structural challenge of funding, grant restrictions and academic processes. In moving forward proactively, participants envisioned a mediator to ‘bridge’ the autistic and research communities, as well as a resource that could provide mentorship and training to autistic individuals, autism researchers and trainees.

The following chapter offers a discussion of these findings via reflective commentary and integration with the literature. The thesis then is concluded by conveying recommendations from these findings, and offering study limitations in considering this study.

## Chapter Six: Discussion

The generosity and openness of focus group and interview participants resulted in rich insights which offer important information that cumulatively supports partnership and allyship in autism research. Such insights recommend that allyship should be presented not merely as a single or ‘stand-alone’ component or phase of a study (i.e., during knowledge translation or data collection), but rather a research ‘way of being’ that is pervasive across all phases of research, including well before a study is formally initiated (i.e., when a study is designed, before a grant is developed and submitted). In their analysis of autism studies utilizing PR, Jivraj et al. (2014) found that only a single research team (Nicolaidis et al., 2011) had fully embraced the notion of PR with autistic people through all phases of their work. Since the time of their review, however, a significant body of work by research groups around the world has recognized the necessity for increased collaboration and autistic inclusion in autism research (AutismCRC, 2016; AASET, 2017; Pellicano et al., 2017; Cascio & Racine, 2018; Cascio et al., 2019; Gowen et al., 2019; Fletcher-Watson et al., 2019; Milton et al., 2019; Nicolaidis et al., 2019).

In the current study, participants strongly endorsed meaningful collaboration and partnership in all phases of the research process, including before and after traditional phases of research (i.e., project conceptualization and grant proposal through to knowledge mobilization), and further suggested that this approach extend beyond research. The message shared can be understood as a *call to action* for deeper discussion and meaningful collaboration in advancing and actioning allyship ‘on the ground’. This chapter provides further discussion and analysis of notions that have emerged from these findings. For the discussion that follows, I have divided

the research process temporally across research phases, continuing the organization from the previous chapter.

## **I. Pre-research and Inquiry**

### *A Way In/Bridge*

Participants offered rich information which suggested that building, strengthening and creating space for research relationships before a research project begins, requires intentionality, sufficient time for engagement, communication, creativity and patience from both autistic individuals and autism researchers. Reflecting concerns regarding early phases of partnership, researchers expressed hesitancy in how to go about creating these relationships in the first place. A level of vulnerability was acknowledged among everyone involved, to be met with authenticity and commitment that was described by participants as essential to the ultimate aim of strengthening and developing research partnerships. A ‘community bridge’ (e.g., mediator group) potentially could provide researchers and autistic participants a way forward for increased communication between these groups. Such steps forward seem promising in intentionally treading a proactive path toward incrementally, authentically learning together and collaborating in the ultimate aim of engagement. Feedback loops and evaluation seem important in incrementally monitoring progress forward as well as addressing any hurdles in this process.

There is precedent for new and deeper ways of collaboration between the autistic and researcher communities. For instance, encouraging emergent engagement can be found in academic/community partnerships such as AASPIRE, which is co-directed by an autistic and

neurotypical researcher (Dr Dora Raymaker and Dr Christina Nicolaidis), along with the engagement of a ‘Community Council’ and ‘Academic Council.’

The suggestion of creating a ‘mediator group’ may increase opportunity for both the autistic community and autism researchers to gain ‘on the ground’ experience, knowledge in, and commitment to, the area of allyship, mutual partnership and research. Aside from merely connecting individuals to research opportunities, a mediator group would allow researchers to access rapid autistic community-imbued advice on pressing community needs and research ideas, seek feedback on manuscripts and other knowledge mobilization methods, access feedback on project proposals, study designs and grants, gain support and engagement in these research ideas, encourage critical reflection on research partnerships, and enact impactful knowledge translation. As a mutually beneficial resource, this kind of group could increase the accessibility to research for the autistic community who, it can be argued, are the first-line or essential ‘stakeholders’ in, and beneficiaries of, autism research (i.e., individuals with actual lived experience). Accordingly, their integral involvement—along with that of researchers—in this process seems essential to the ultimate aim, quality and impact of this research. Moreover, scrutiny of the research and research process by autistic people, seemingly would offer the research community a proverbial ‘litmus test’ of viability and relevance for the autistic community. Accordingly, an inclusive, allied approach offers a positive direction in proactively moving forward.

This proposed idea of an embedded community advisory can be understood to have its roots and foundation in the social model of disability, with leanings towards emancipation. For example, in its push to encourage researchers to be critically reflective of their

research/community practice, an allied academic/community group would not simply place increased responsibility on the researcher, but offer support and lead the way in ethical research partnership and claiming a space for autistic people in community/research partnership development. The necessity of commitment and critical reflection is validated by Cascio et al. (2019) who encourage researchers to “acknowledge stigma, stereotypes, and past experiences of having been excluded that impact the research process” (p. 26). In this way, the social model of disability places emphasis on the roles, values and actions of researchers (i.e., the external environment in the social model), while again valorizes and amplifies the essential expertise of lived experience (i.e., emancipation from the role of research subject).

### ***Representation***

This kind of autistic-led shared initiative is complicated by what is viewed to be as an inherent disparity in the lack of research involvement by non-verbal and minimally verbal autistic individuals. This gap further challenges the notion that the perspective of the autistic community must be intentionally inserted in the research enterprise as fully and broadly as possible – in shifting the ‘research in autism’ culture to a ‘research inclusion-based’ culture.

Milton et al. (2019) identifies this challenge, noting that in order to truly be *doing* participatory work with the autistic community, this gap and the breadth of the population needs to be addressed. Regarding the work of the Participatory Autism Research Collective (PARC), Milton et al. (2019) describe, “The PARC group has been successful and continues to grow, yet to be living up to its name it will need to find ways of widening participation for those with more considerable communication or intellectual impairments, or from autistic people who also

occupy intersecting marginalized identities” (p. 87). Wright (2019) problematizes this gap in autism research representation, reflecting on the Belmont Report (key ethics and principles for research practice in the United States). This report states, “The selection of research subjects needs to be scrutinized in order to determine whether some classes ... are being systematically selected simply because of their easy availability, their compromised position, or their manipulability, rather than for reasons directly related to the problem being studied” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 6). A methodological way forward in addressing this exclusion in research participation has been advocated (Milton, 2014), and if achieved, could offer informative steps to mitigate this cycle of exclusion in autism research.

Recent research exploring the benefits of being intentional about including autistic participants across a communicative/cognitive spectrum have suggested that choices of methodology could make the difference between inclusion and exclusion of non-verbal or minimally verbal (and potentially cognitively diverse) autistic participants (Nicholas et al., 2019; Tesfaye et al., 2019). This highlights that true inclusion is not limited by thresholds of speech fluency or cognitive expression.

Representation across the autistic community may be made more layered and potentially challenging by the reported preferences of some autistic individuals without intellectual disability, to not be presumed to be communicatively similar to autistic individuals with co-existing intellectual disability. As well, the experience of “masking” may also contribute to the



complexity of representation, where autistic individuals adapt their communication to fit in with others in the rest of the group.

### ***Funding***

Traditional approaches to grant funding were noted to potentially play a role in how partnership occurs (or doesn't occur) in developing a research project. While many academics are well-intentioned and contribute much to the community, productivity-based markers in tenure track trajectories demand research momentum and swift development of research in being deemed a "productive" researcher. This focus on rapid grant access akin to common metrics of successful research productivity, may impede incentives toward the potentially slower relational work in building participatory collaboration. Since academia follows grant guidelines and a tenure-based orientation which may discourage deep and meaningful partnership building with autistic colleagues on research teams, requirements for "productivity" seemingly merit structural and behavioural change in academia and Tri-Council and other funding structures. For example, ensuring that grant funders and university promotion committees value meaningful community engagement emerges as a pressing priority. Stahmer et al. (2017) identifies how, by starting with community engagement, the research team can move forward well:

The group can then consider funding sources and operational processes that ensure balance of power and development of mutually beneficial products. These types of partnerships can lead to innovation in research and at the same time be highly productive for the community. (p. 260)

Achieving this important end will require concerted effort at an individual level particularly by researchers and academia, including shifts as described in Chapter 5. Indeed, sustained shifting seemingly entails transformative discussion with university, research/academic and national/international funding structures that currently disincentivize active support to allyship particularly prior to the writing of and access to grants. While incorporating and engaging people on the spectrum is increasingly invited by research bodies, this engagement is not yet well-remunerated or supported structurally. Continued conversation and advocacy for establishing infrastructural support to this end, is integral to sustained implementation.

## **II. Beginning of Research**

After grant funding has been obtained and actual work begins on a given research project, focus group participants described the importance of the general approach that researchers bring to the partnership and the expectations that are communicated from the beginning, including notions of authentic engagement and moving beyond tokenism, as outlined below.

### ***Authentic Engagement***

Authenticity was described as a key element for both autistic individuals and autism researchers to bring about a research partnership. The difficulty of defining what is ‘authentic’ and what is not, however, was a particular challenge in the focus group dialogue. Beyond individual research teams having this conversation, these notions of deeply and critically examining concepts of ‘on the ground’ authenticity invite broader discussion about authenticity in research and where that could lead in other microcosms of community and daily living. Questions that may support this reflective process include whether authentic research can be

successfully achieved by all (or most) autism-focused (or perhaps more broadly, disability-focused) researchers, or if the qualities of authentic engagement are inherent to certain substantive foci and research approaches, while perhaps are less present in, or amenable to, other approaches. I would argue, however, that it is important not to capitulate to non-partnership simply due to relying on traditional models of research and variant paradigms such as the medical model, that seemingly have permeated conventional autism research over recent decades.

Researchers have traditionally played a role in setting expectations for research participants, and clearly articulating the roles of each individual for each phase of the project, which has been in keeping with established practices. However, a researcher-led/dominated approach may be counter to what is intended and may impede meaningful and authentic engagement and partnership. This is potentially where a mediator/third-party group (such as described in the section on Pre-research and Inquiry) may play an important role. Such a resource may serve to better balance what participants clearly described as inherent in the power imbalance that has been historically present in research and has thus impeded equity of engagement by members of the autistic community. In moving forward, a mediator group could facilitate a conversation on guidelines and principles of practice between researchers (including autistic team members) and autistic participants and in so doing, offer support in being ‘on the same page’ relative to understanding responsibilities and expectations towards moving forward as partners.

### ***Moving Beyond Tokenism***

A concern expressed in this study, and heard throughout my time as a research assistant, was the reliance on the use of ‘self-advocate advisory committees/panels’ which, although perhaps well-intentioned, risks becoming the primary means of engagement with the autistic community, which could be construed as tokenistic. Participants conveyed elements of the academic process (e.g., grant deadlines, publication deadlines, push for productivity, etc.) that pressure researchers toward particular decisions based on imposed values of an academy-defined orientation to efficiency via independence in research practice. While notions of implementing an advisory (versus a decision making) committee may be a part of that orientation, arguably this does not go far enough and may not achieve aims of true inclusion in the aim of community betterment and thus higher quality engagement with stakeholder communities. Although current practices and approaches, as described herein, may be viewed as practical and conventional in moving a research project along, the relational qualities and purpose of the research itself arguably may not be optimally nurtured or achieved; hence, further development of allyship practice indeed is warranted. The current tension between what researchers may want from a research project (i.e., meaningful engagement, community inclusion) versus what they need to *do* in conducting a project (i.e., data collection, access to grants, compliance with funders, publication, achieving university tenure and promotion), may fundamentally or practically clash with, and potentially derail, what the autistic community wants and needs (i.e., meaningful engagement, community inclusion, fair compensation).

### **III. Throughout the Project**

#### ***Group Dynamics***

As described in Chapter 5 (Results), group dynamics are a significant element that can impact group work in research projects – a particularly poignant consideration in group-oriented approaches/methodologies such as PR. These dynamics can manifest themselves as intrinsic to micro-level research elements such as individual personalities, approaches and preferences. As well, this can be influenced by both the researcher’s and the autism community member’s prior experiences, expectations and goals of the project, stress-coping skills, self-awareness in group settings, and awareness of how an autism diagnosis impacts an individual’s social and group work experience.

If researchers find they are not ‘on the same page’ as another member of the research team, they may avoid working with that individual. This is where group dynamics become an important consideration because it seems that a community-minded project would necessitate researchers having an open mind to work and collaborate with autistic individuals.

Disagreement and conflict, for example, are relatively common among groups, and should not necessarily be attributed to an issue specifically in working with autistic individuals nor a reason to dissuade inclusion in research teams. On this topic, Nicolaidis et al. (2019) provide a personal and professional challenge to researchers: “We strongly urge academic researchers to continuously consider how their power, privilege, and potential biases may be affecting the collaboration and to avoid pathologizing community partners when disagreements arise” (p. 2012). As it relates to building positive relationships, power dynamics were described in the

focus groups as a challenge to proactively embrace and address. Nicolaidis et al. (2019) recommend the use of “power-sharing” (p. 2011) communication methods, such as mutually agreeing on ways for the group to best communicate, collaborating on appropriate accommodations to suit communication needs, and encouraging constant reflection.

### ***Personal and Professional Circles***

Relative to research collaboration, research projects are typically led by a team of academics who work in similar ‘circles’ of scholarly focus. For example, an autism researcher in a given city and university is likely to meet and collaborate with others at the same university who also conduct research in the same or similar areas. As well, these researchers tend to participate in conferences, both nationally and internationally, on specific topics, which provide networking opportunities for like-minded researchers to partner and collaborate. These ‘circles’ are an ingrained and consistent process and context in research environments, and while there are some examples of progressive work being accomplished to open up these circles (i.e., highlighting of autistic researchers at recent International Society for Autism Research annual meetings), the non-academic autistic community tends to be left on the outside, often with little or no awareness about past or upcoming opportunities related to research or knowledge sharing/mobilization. I strongly urge more inclusion for the autistic community in these circles, including conveying information that is accessible. An informative example of such innovation is in the editorial board of the peer-reviewed journal, *Autism in Adulthood*, which explicitly engages the autistic community in its editorial board, and requires information that is accessible to a range of audiences including those across the autism spectrum.

### *Bridging Different Identities*

Complicating the notion of inclusion within specific social and professional circles, there are realities that need to be considered and respected, including deep regard for the lived experience of autistic researchers. In discussion with Laura Gilmour, an autistic PhD candidate at the University of Alberta, she describes feeling a “tug of war” (Personal communication, January 7, 2020) in attempting to navigate the personal ‘circles’ of being an autistic individual as well as the professional circles of being an autism researcher. This insight further emphasizes the need for the autistic and research communities to *ally well* in order to most openly and respectfully understand individuals’ diverse personal and professional experiences, as well as to ultimately collaborate in respectful interaction and ultimately advance higher quality outcomes that are meaningful for autistic people.

Non-autistic researchers are called upon to consider the additional personal challenges that autistic individuals collaborating on, or engaging in, autism research may experience. These challenges may be as a result of the social challenges inherent in the experience of autism, or perhaps, having to constantly navigate between an autistic and non-autistic perspective. Milton et al. (2019) capture these challenges in their description of the “emotional labour” (p. 86) experienced by some autistic researchers:

Constantly engaging with a huge amount of violent predominant autism discourses, based on dehumanising and infantilising medical models... engag[ing] in predominantly non-autistic autism discourses as well as non-autistic colleagues whilst managing our own

emotions regarding the dominance of non-autistic autism discourse...[and] the constant need of having to re-evaluate our beliefs and alliances. (p. 86)

The experience of “masking” shared by one autistic participant (see Results, Chapter 5) is echoed in Milton et al. (2019), whereby the emotional toll on autistic individuals created by these challenges, highlights the power differential at play with non-autistic researchers who likely are not required to navigate the same emotional work and subsequent repercussions. Beaumont (2019) discusses the specific experience of “masking” and the challenges that go along with it:

The benefits of being able to mimic other people in order to fit in socially are outweighed by the tremendous physical, mental and emotional toll it takes on a person. Despite this, I am usually completely unaware of employing this tactic, only hours later being so exhausted that my usual 10-h sleep increases to a 14-, 16- or even 18-h slumber. (p. 92)

This experience of “masking” and feeling pressed to conform within a neurotypical setting could be somewhat eased by creating safer research spaces to which the autistic community can ‘bring themselves’ (see Results, Chapter 5). Being ‘yourself/themselves’, in this context, suggests the need for creating research work environments in which individuals are intentionally made to feel ‘welcome’ and comfortable such that they know they will not be judged or removed from the group for variant ideas or for things outside of their control (i.e., being themselves). This kind of safe space in autism research could provide improved access to research engagement for the autistic community, thereby offering increased opportunities for the autistic community to directly impact autism research priorities, processes and outcomes. As described by Beaumont (2019), “The PR [participatory research] approach allows the individuals



to whom the research directly refers have a greater say into and be personally involved in shaping their own future” (p. 91).

The argument for engaging in work on ‘safe spaces’ is further supported in addressing misconceptions among some researchers that all autistic individuals are going to be difficult to collaborate with; however, the same misperception likely exists for autistic individuals hesitant to engage with researchers in what is known as the “double empathy problem” (Milton, 2012, p. 884). Richman (2019) summarizes this problem, observing how “neurotypical researchers are as likely to have difficulty understanding autists as vice versa” (p. 59). Overall, these potential communication challenges between the autistic community and autism researchers perhaps speak to a larger challenge of trust and relationship. In the history of autism research, autistic individuals have experienced being the passive ‘participant’ or ‘subject’, much in line with a traditional positivist research approach; however, with continued critical analysis, there has been a demonstrated need for, and encouragingly, some steps forward in advancing change and flexibility in autism research. As corroborated by Cascio et al. (2019):

When research studies have not taken the needs of participants on the spectrum into consideration (e.g., by forcing eye contact or participation in large groups without attending to sensory needs), participants and their parents have felt misunderstood and lost trust in the research process. (p. 23)

This suggests the need for inclusion, understanding and change. The need for building proactivity and inclusion in autism is pressing and indeed urgent.

Of further consideration at the time of writing, there have been additional challenges introduced by the COVID-19 pandemic such as social distancing that largely precludes in-person research meetings. However, along with these pervasive challenges, potential opportunities may be emerging. While face-to-face engagement may continue to be limited for some time, other ways of communicating have been increasingly relied upon that may be more commensurate for many autistic individuals e.g., online communication. This may invite consideration of means of communication and engagement that accommodate various preferences for engagement. Continuing to consider and accommodate such variation in research engagement seems integrally important even after pandemic restrictions lift and traditional in-person meeting access resumes.

### ***Group Matching***

Speaking to the challenge of community representation in research, some sentiment from amongst the autistic community and researchers reflected advice to not assume that all autistic individuals should “naturally” be matched together in group work. For example, individuals who communicate by talking may not wish to be working with a group of people who communicate non-verbally, despite all those individuals identifying as autistic. An element of such discomfort was captured in Chapter 5 (Results), and adds a layer of complexity and planning for research teams in seeking to represent the perspectives of autistic individuals across communicative categories. My experience as a research assistant on a study specifically related to the topic of minimally verbal/non-verbal communication in research (see Nicholas et al., 2019) played an important role in my understanding of this challenge. Overtly and sensitively

addressing these questions in ways that support respectful solutions are suggested. This speaks to the work faced by the research community, and by society in general, in considering how to effectively include and represent the perspectives of minimally verbal and non-verbal autistic individuals as well as all autistic people, amongst those with other various abilities and differences.

This priority for inclusive engagement in a research context that deeply engenders ‘nothing about us without us’ can also be seen as a reflection of similar challenges of inclusion faced by the neurodiversity movement, as described by Hughes (2016) and discussed in Chapter 3. Ultimately, meeting individuals ‘where they are’ is critically important, and the aims of a socially just and inclusive research community should guide various communities including those that have a bearing on, and are a part of, the lives of autistic people.

To broaden perspectives and engagement across a range of researchers who are engaging in potentially new ways of doing research, resources such as a mediator group may be helpful in coming to mutually beneficial approaches in expanding opportunity for authentic and ‘fair’ engagement. Notwithstanding important advances and opportunities for moving forward, I do not want to gloss over the challenges that may incline researchers toward a return to the status quo in their research. Careful consideration of the challenges and mitigating strategies are needed, including how to navigate moments of disagreement and how researchers can authentically share power such that principles of partnership and allyship are truly applied, extended and sustained.

### *Toward Broader Systemic Change*

While the strategies described to this point are arguably practical and could potentially be feasibly implemented and incorporated into research practice and advocacy, they can also be seen as limited due to their reliance often on one-sided efforts of the autistic community. When supported by non-autistic allies, these proposed strategies tend to be largely dependent on the idiosyncratic efforts, personal commitment and relational capital of individual researchers. These strategies may be integral to meaningful change taking place in autism research; however, this can be understood as taking place at a micro level and may risk research innovation ‘one offs’, placing the impetus for change on the individuals including autistic persons who have historically borne the most harm as a result of a lack of meaningful partnership in autism research. Moreover in such instances, change is not structurally embedded in the bastions of institutional research offices and policy.

In line with critical reflection, and more specifically a social model of disability, the role of the larger systems that govern and structure the research enterprise must be called upon to play an active role in this imperative work of relationship-building and allyship in research development. This may begin with post-secondary institutions and their research ethics boards, as well as major funding institutions (mezzo/macro systems), and further work is arguably required at societal and attitudinal/values (chrono system) levels to discursively resist inequities that have historically contributed, and currently contribute, to such pressing challenges. Beyond impacting the research landscape, advancement towards a more relational and allied approach

between researchers and the autistic community perhaps has the potential to address systemic ‘othering’ of autistic individuals, and people with disabilities more generally. May it be so!

### **Redressing Barriers: Toward Action and Change**

These findings, as well as those of other studies (Beaumont, 2019; Cascio et al., 2019; Milton et al., 2019; Nicolaidis et al., 2019; Richman, 2019), acknowledge some complex notions of identity and intra-group and relational dynamics that can make strengthening research-community partnerships a challenging quest. It is acknowledged that in moving forward, there needs to be willingness, intentionality and expectations of collaboration that are shared by involved autistic community members and autism researchers. Currently, there seems to be some momentum and political commitment to ‘push’ for such transformation, particularly given precedent in a range of countries (e.g., AutismCRC (Australia), AASPIRE (United States), AASET (United States), PARC (United Kingdom), Autism Research Ethics Taskforce (Canada)). We variably consider (or like to consider) that Canada aims to be proactive relative to disability research and practice. Accordingly, not engaging and embracing this transformative shift via community engagement would seem out of step with our aspirational ethos and commitment.

At a structural level, inclusive and participatory research practice is justified by Canada’s ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2010, and the accession to the Optional Protocol of the UNCRPD in 2018. For example, a general principle of the UNCRPD is “full and effective participation and inclusion in society” (United Nations, 2006, p. 5). Article 21 (Freedom of expression and opinion, and access to information) may have significant importance for the rights of people with disabilities

to be engaged in research when it states that society, “shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice” (United Nations, 2006, p. 14). Cascio et al. (2020, 2020b, 2021) likewise reference the Universal Declaration of Human Rights in upholding people’s rights to accessing, and participating within, scientific process and knowledge, as well as highlighting the critical role of the research ethics field in furthering participants’ rights.

The openness and vulnerability shared by researchers in this study provided important learning and likely speak to a level of willingness and commitment to consider greater engagement in allied research on the part of certain echelons of the research establishment. Although researchers such as those represented in this study are increasingly considering partnership decisions (e.g., seeking autistic advisement early in the research process), these findings conversely illuminate uncertainty among researchers regarding how to optimally connect and engage with the autistic community. These reflections reveal what seems like progress in the field, but also concern that authentic engagement of autistic people may yet be illusive and pathways forward are uncertain. Continued research and practice in advocating for true and sustained shifts are advocated.

### ***Partnerships in Cross-sectional or Experimental Research***

Additional challenges are noted in particular research contexts. As an example, participants described unique challenges to allyship where a study has a large sample of

participants (e.g., hundreds, or in some cases, thousands of participants) such as in some quantitative designs, which are common in autism research (e.g., genome sequencing or biomarker studies). While PR has tended to be synonymous with the inclusion and collaboration of research participants, there may be an assumption that this research is primarily qualitative and exploratory in nature, rather than espousing other approaches and methods. This notion that participatory approaches are incompatible with experimental and other study designs, is challenged by Yusuf and Elsabbagh (2015) where they argue that elements of PR can be found in ‘biomarker autism research’, with no evidence of impact on the quality of the data.

In considering layers of complexity relative to studies’ aims and potential approach, it may be helpful to consider the intentionality of biomarker research and its potential of utilizing a PR approach. On the one hand, increased participation of autistic individuals in all autism research is important; however, there is noted opposition from the autistic community to the prioritization of biomarker research (Nicolaidis et al., 2011; Pellicano, 2014). Relevant to, yet beyond, this debate, inclusive dialogue about research priorities emerges as pivotal among autism researchers and the autistic community. Of note, Yusuf and Elsabbagh (2015) provide a helpful discussion of some of the challenges that reflect PR in the contested context of biomarker research. Their findings reveal a current lack of research exploring the possibilities for this area, indicating the need for critical reflection and input from the autistic community, larger stakeholder community (e.g. families, service providers, policy makers), and research community.

## **Toward Allyship**

Any research regarding people on the autism spectrum, whether related to quality of life, causation or other substantive foci, has the opportunity and potential to engage the perspectives of autistic people. This research has emerged as an appropriate space for researchers to adopt an allied stance, and promote participation and collaboration in research as a way of respecting and allying with the community. In this way, the diverse and sometimes challenging perspectives of the autistic community regarding the intention and historical oppression of biomarker or causation research could be heard where otherwise it may be excluded or muted. Although historically (and even currently), this intentional inclusion of dissenting views is controversial and may be disquieting, such openness to new and open conversation could facilitate discussion in ways that advance autism research and perhaps open new vistas of inquiry, while ensuring that multiple stakeholder perspectives are heard and taken into account.

Cascio et al. (2019) address the question of perceived negative impacts of broad inclusive dialogue, describing it as a misperception and of something that researchers can still work towards. They contend, “While a randomized controlled trial will look very different from a single-subject case design or person-centered ethnography, researchers conducting these studies can still reflect on the goals of person-oriented research ethics” (p. 22).

## ***Personal Relationships***

Participants in this study expressed concern that collegial or personal relationships among researchers and participants such as those reflected in this research (e.g., convenience sampling), may not be amenable to other research aims such as ‘testing’ a hypothesis (such as in



experimental research). Concerns were raised that such pre-existing relationships may introduce a bias that can compromise the quality (e.g., validity, reliability) of a study. However, that perspective was balanced with an acknowledgement that these same relationships could be beneficial to research quality, including increased relevance of the research to the autistic community, quality of outcomes, and deeper knowledge translation/community engagement for knowledge mobilization and impact. This combination of the ‘pros and cons’ of relational research, as described in the focus groups, are reflected by other researchers, such as Beaumont (2019) and Richman (2019). Beaumont (2019) describes some of the positive potential from PR that embraces relational process: “There grows a level of trust between the participant and the researcher that engulfs the entire collaborative process leading to a higher quality of information retrieved and a strengthening of relationships between both parties” (p. 91). Richman (2019), however, highlights some of the complexities that exist in these kinds of relationships, suggesting,

Participation in autism research is complicated by the potential mismatch between the goals of researchers (who are often oriented toward curing or preventing autism), and the goals of autists (many of whom find research aimed at cure or prevention profoundly offensive. (p. 59)

Richman (2019) further describes the possible conundrum that individuals (both researchers and potential participants/contributors) can find themselves in while participating in a research project, including instances in which each group might desire completely different aims from the relationship without those aims being communicated. Exploring these

complexities further, Richman (2019) points out that all of these scenarios can exist in research with positive outcomes; however, where an individual is actively opposing the aim of the research, this may have an impact on “valid data and conclusions” (p. 61), and may risk inauthentic consent. On the other hand, if the researcher and participant/contributor is willing to engage in discussion and openly learn from each other, this may provide a valuable opportunity for understanding and exploration. Overall, it is important to acknowledge that a multitude of factors can impact research outcomes, from the mood of individuals at a research interview to comments made by participants before or after engaging in research. Cascio et al. (2019) capture the subjectivity and layeredness of these elements in suggesting, “How close the researcher feels to the participants could impact how the researcher interprets or discusses results, for better or worse” (p. 52).

These various perspectives heighten continued consideration and critical inquiry about the potential inclusion of varied stakeholders’ meaningful input in autism research. Based on these findings and the perspectives presented herein, there remains a concern that the autistic community has traditionally been largely excluded from fundamental processes and priorities of autism research. Emerging recognition of autistic rights and a growing commitment to a social model of disability render the widespread exclusion of autistic people’s involvement in endeavours about autism largely in question and within the realm of unacceptability. This persuasion has important implications on present and emerging conventions in autism research, as well as on other elements of life that reflect and have a bearing on autistic people.

## **IV. Conclusion of Research**

### ***Knowledge Mobilization***

Focus group participants discussed the importance of relevant knowledge mobilization activities in relation to community engagement and the impact of research. Research that is largely restricted to an academic audience due to exclusive publication in academic journals was seen as inhibiting community stakeholders who need, yet typically do not have access to, research due to restrictive journal subscriptions and academic discourse. This challenge can be understood as being linked to a history of positivist research in academia where ‘knowledge’ is seen as created exclusively by (and largely for) researchers through data collection and analysis.

A critical challenge to this pattern and orientation contends that traditional research products, as developed for and thus understood by the researcher community, dissuade community engagement and feedback relative to generated knowledge. Yet there are many examples of research teams thinking deeply and creatively about knowledge mobilization (Beaumont, 2019; Cascio et al., 2019; Milton et al., 2019; Nicolaidis et al., 2019; Richman, 2019), with benefits from widespread sharing of research findings and amplifying models for the continuous improvement of partnership in autism research.

Beyond substantive post-study knowledge sharing, some participants described the need for increased sharing not only at the conclusion of research projects, but also throughout the process. This is in line with researchers such as Beaumont (2019) who recognizes the benefit of sustained partnership for both the researcher and participant. For the researcher, Beaumont (2019) observes, “the retaining of participants means access to long-term data from willing

participants, and less time spent recruiting” (p. 91). Reflecting on their personal experience as both a participant and partner in research, Beaumont (2019) highlights how this engagement has been “a deeply empowering and emotive venture...allowing access to a continuing stream of new research data” (p. 91). Clearly, engaging stakeholders – researchers, autistic participants, researcher partners, knowledge users, etc. –are critical in advancing the research endeavour, including moving to create impact and seeking socially just and proactive advancement of autism research.

An idea presented by the autistic community was the desired opportunity to consult and advise on drafts of written articles and reports. This engagement could be further integral in local, provincial, national and international research presentations. Study results suggest that consultation or advisement by the autistic community may create a stronger and more accurate picture of outcomes and impacts, yet this requires researchers to engage and utilize autistic feedback. A mediator group, as presented earlier, could potentially facilitate such reflection and feedback processes for the mutual benefit of the autistic community and autism researchers, as well as for the advancement and application of knowledge in general. This is further supported by Milton et al. (2019) and Pellicano et al. (2017) who have discussed the potential for mentorship and peer-support between interested community members and researchers. Nicolaidis et al. (2019) highlights AASPIRE’s practice of regular evaluation at the end of meetings as well as at key stages of collaboration, thus exemplifying potentially more inclusive research practices.

### ***Fair Compensation***

In addition to inclusive knowledge mobilization, some focus group participants called for fair compensation for the input of autistic contributors to research, in terms of financial reward and chances to build life skill opportunities in contributing to health and well-being. As described in Chapter 5 (Results), internships and training may provide valuable learning and vocation-development opportunities.

It seems that tangible rewards for participant research engagement often comes in the form of a nominal honorarium or gift card which is appreciated by participants, but is insufficient relative to some autistic people's individual financial needs, and not commensurate with their expertise and contribution of time, energy and expertise to a given study. Nicolaidis et al. (2019) similarly highlight the potential of research engagement to translate into life and/or employment experience, including, but not limited to, financial compensation. Additionally, Cascio et al. (2019) encourage researchers to more deeply consider the potential for positive impact on participants and support their role in fostering community inclusion. While additional non-financial benefits (as well as financial compensation) may advance remuneration rates/formulas, results of this research (Chapter 5) indicate a need for open discussion that examines what would be most appropriate for individuals involved in studies as well as for co-researchers and collaborators.

### ***Recognition vs Anonymity***

Autistic researchers have described the unique challenges they experience in balancing their research involvement as a participant versus a research partner, contributor or author.

Transparency, openness and respect for these co-existing differences and the potential tensions therein (as described earlier regarding the importance of authentic engagement) are critical in these situations in order to respect people's lived experience. Laura Gilmour, an autistic self-advocate and autism researcher quoted earlier, shared, "I find that sometimes protection of privacy is utilized in a way that borders on IP [intellectual property] theft. Anonymity should be an option and not a requirement of participation for projects that involve interviews and focus groups" (Personal communication, January 7, 2020). This invites critical consideration of options and opportunities in opening new space for autistic individuals to occupy research spaces both to a greater extent and potentially in new ways than have traditionally been provided. Continued research and application of learning and research praxis are needed, yet with the intentional inclusion of autistic people in this ongoing inquiry and discussion.

### **Limitations**

This thesis is notably focused on allyship and partnership. Yet in addressing this topic, the project admittedly could have enveloped more of the elements it aims to explore and promote. This relative lack, in part, reflected the structure of my Master of Social Work (MSW) program and the limited time available as a MSW student. By the time I was being encouraged to submit my application for Ethics certification, I felt like I had already gone too far to justify categorizing my research as a particular form of PR (i.e., CBPR or PAR), and found it more appropriate to state that it contains 'elements' of PR as I had not yet consulted autistic colleagues in all research aspects – particularly, early concept development elements – as fully as a PR study would invite. On the other hand, I have consulted with a range of community members

throughout the research process, and am grateful for their ongoing engagement, commitment and deep contribution to this research.

Recruitment was targeted towards autistic individuals and researchers who were comfortable communicating verbally, thus excluding autistic individuals who communicate in less-verbal or non-verbal ways. This was a difficult recruitment decision to make as my initial interest in bringing researchers and autistic groups together was meant to be inclusive of communication across the spectrum. My understanding shifted, however, after consulting with some autistic individuals who expressed their discomfort at being included in the same focus group as an autistic person who does not engage at a similar cognitive or communicative level. Yet, this work could have engaged various groups across communication and cognitive functioning. Cascio et al. (2020b) provide further guidance on this topic, advocating for a strengths-based and respectful approach which assumes capacity before being demonstrated otherwise. Of this approach, they describe,

The guidepost of respect for personhood encourages researchers to actively enhance the ability of people with autism to contribute to research by soliciting their feedback and by designing the research process to take into consideration their needs, preferences, or priorities. (p. 3)

Ultimately, this has been an important learning experience that has challenged me personally and professionally, opening doors to rich and critical questions and opportunities for future exploration.

Convenience sampling as a recruitment method may be viewed by some as limiting and problematic in the sense that many of the participants (both researcher and autistic) had a working and/or personal relationship with myself. While I believe this facilitated an ease to the conversations, as well as having been an intentional way to engage with autistic individuals, there is a possibility that these pre-existing relationships impacted what was shared in the focus group, as well as how it was shared. Also, it is unknown how the data would have been different had I engaged a different group of participants where a personal relationship did not pre-exist. Sampling also took place in one geographic region and engaged a small sample of participants.

The decision to invite autistic individuals and autism researchers to the same ‘table’ invited some concerns expressed by colleagues. It was recommended that these two groups should be separated into distinct focus groups in order to eliminate the possibility of autistic or researcher participants censoring themselves on behalf of the other group. The University of Calgary Research Ethics Board also initially made note of this concern; although they ultimately approved this mixed focus group configuration. However, it was concluded that the spirit of the study called for collaborative discussion on how to work *together* and it seemed important to represent and model that through an inclusive discussion. Notwithstanding this commitment and approach, the influence of mixed groups on data and openness in sharing among each participant group is unknown; however, there seemed to be open and animated discussion that was vibrant, and participants reported their group participation as authentic. The ‘Member Checking E-mail’ also attempted to provide an opportunity for all participants to follow-up with me privately if



there were thoughts they did not feel comfortable sharing in the focus group setting. That review corroborated the engaged and frank conversations from the initial focus groups.

Initially, this project aimed to compensate individuals equal to what I personally earned as a research assistant. Despite the critique raised by some participants in this study regarding the common use of gift-cards as honorariums, this thesis did ultimately provide gift-cards as a way of compensating both autistic and researcher participants. This decision was made in an attempt to balance the equitable spirit of the study with the Research Ethics Board's concern that substantial amounts of compensation may unduly influence participation in the study. In the end, participants were provided the opportunity to request gift-cards to specific outlets or services, and the amount ultimately was comparable to my hourly earnings as a research assistant. The complexity of navigating approval for these kinds of honorariums and compensation validates the notion raised in this study that further reflection on 'fair compensation' is warranted.

Finally, researchers' willingness to participate in this study may have reflected a persuasion toward inclusive models related to allyship. Despite this likelihood, there was variation and concern about how allyship and collaboration would emerge across the range of research approaches and foci. Given this sample and findings, it may be that a more diverse sample of autism researchers would be less favourable to autistic inclusion in research, particularly across the continuum of research approaches and substantive areas of inquiry. These findings encourage further research across diversities including autistic persons and their represented range of communicative expression and cognition, and researcher disciplines,

methodologic and theoretical approaches (e.g., PAR vs. experimental research), and substantive areas of inquiry within autism research.

## **Implications**

### ***Critical Social Work Practice***

This thesis research meant to invite critical reflection on traditional notions of research engagement between academics and the autistic community. This was supported and scaffolded by a critical theoretical framework which has guided this study and helped situate my understanding of what was heard and interpreted. This approach seems appropriate and in line with the thesis topic, as shown by the nature of critical theory which purportedly tends to be (a) wary of a positivist orientation, (b) resistant to socio-historical oppression and marginalization, (c) open to consider and address structural underpinnings in identifying oppressive phenomena, (d) open to critical reflection of dominant thinking, (e) supportive of personal choice and human rights, (f) informed by the potential for structural change, and (g) mindful of the nature of these changes to be made through daily acts of liberation and education (Agger, 2006).

This expansive, evolving framework provided the guidance and structure necessary for this study, and invites practicing social work researchers and practitioners to follow a critical, anti-oppressive process. Critical tenets of reflexivity, emancipatory approaches, positivist critique, and structural resistance can be considered by social workers (in research, clinical and community settings) in the aim of social justice via working with the autistic community in the pursuit of what is of importance to that community in a self-determined future.

A concern across all research, but particularly research requiring the perspectives of marginalized communities, is that systemic challenges as a result of economic retrenchment, particularly locally due to a currently constrained economy and COVID-19/post COVID-19 economic austerity, could impede progressive and proactive models including the expansive opportunity for autistic people to be engaged, and supported in that engagement, within the research enterprise. We need to ensure progress such that proactivity in advancing research opportunity for the autistic community are heightened through initiatives that address engagement by and with autistic individuals, as well as research and leadership processes that are equitable and sufficiently resourced in our ultimate aim of the full inclusion and self-determination of autistic people.

### ***Research***

This study invites autism researchers (whether social workers or otherwise) to bring a critical perspective to their areas of inquiry and conduct of research, with the aim of being aware of, and taking action to rectify, power imbalances in the research process. This research calls for radical reshaping of inclusion in research and other realms of community life for autistic people (e.g., civic and community inclusion), and the time for this reshaping is here; indeed, groups in the research landscape are already engaging in these types of processes (e.g., AutismCRC, AASPIRE, AASET, PARC, Autism Research Ethics Taskforce). The important work of these key research partnerships continue to provide the momentum for moving forward in a collaborative way.

Focus group participants in this research offered creative ways of moving forward for both researchers and autistic individuals that advance research (See Appendix E for poster that summarizes these ideas). Examples of recommendations include the following:

- A mediation/advisory which would navigate between the autistic and autism research communities,
- A training/orientation element which would connect autistic individuals to research information and opportunities, as well as support researchers seeking to engage with the autistic community; and
- A resource-sharing partnership within, and ideally across, transdisciplinary communities and research or university settings.

### **Summary**

Reflection and discussion of the results of this research offer benefits and challenges to collaborative and allied research that is inclusive of the autistic community and autism researchers. Despite the challenges that arise when attempting to pursue allyship in research, this work supports and informs possibilities for relational development between the community and research worlds.

## **Chapter 7: Conclusion**

Ongoing intentional and open-hearted discussion between members of different groups, while logically simple in conception, reveals a complexity that arises from diversity in group identity and values. While this relational work can be messy, complex and perhaps at times uncomfortable, we are at an important ‘moment’ of opportunity for all involved to experience shared learning, personal/professional development, intersectional relationship building and greater community inclusion.

This thesis invited the autistic community and autism researchers to literally sit at the same table to have what was deemed as needed and open conversations. They identified innovative and insightful means forward by exploring their own experiences, preferences, vulnerabilities and potential opportunities. Overall, the perspectives and ideas shared in this research support collaboration and the inherent value of allyship between the autistic and research community. As one focus group member stated in addressing the topic of allyship in research and the potential for continued relational development, “I think what I’m saying is: it builds community. It’s a way of building community and connecting people with different skills and knowledge in a way that starts to transform our social world.” As I reflect on this study and its results and implications, this phrase as conveyed in the focus group, seems so well-stated.

During this sociocultural juncture in which marginalized perspectives seemingly are increasingly (hopefully) recognized in the public discourse, the work of finding shared and inclusive spaces in various sectors—including research—are strongly warranted, yet likely will require champions who bring vision, strategy, persistence and collaboration. The engagement of

the autistic community in research has accelerated within international initiatives. This ‘inching forward’ towards allyship will require a determination for social justice, empathy, openness and humility that will hopefully continue to evolve in autism research.

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## Appendix A: Recruitment Poster

**How can self-advocates on the autism spectrum and researchers better work together?**

**If you are a self-advocate on the autism spectrum and interested in this question, please see below:**

Two conversation groups will take place in Edmonton. They will address research perspectives and priorities, and how we work together as self-advocates on the autism spectrum and researchers.

There will be pizza and light refreshments available before and during the conversation.

**If you are interested in participating, please contact Jesse Orjasaeter at:**

**Email:**

**Phone:**

This study has been approved by the Conjoint Faculties Research Ethics Board of the University of Calgary



## **Appendix B: Convenience Sample Recruitment Email**

Hi \_\_\_\_\_,

We are embarking on a study that is examining partnership and allyship in autism research between self-advocates and researchers. I've attached a poster that further describes the project.

You are invited to participate in a group discussion or individual interview.

If you are not interested in participating, please be assured that this is absolutely fine as participation is voluntary.

Thank you for considering this study, and please let me know if you would like more information about the study and/or would like to participate.

Kind regards,

Jesse Orjasaeter

MSW Thesis Student

Faculty of Social Work (in Edmonton)

University of Calgary

## **Appendix C: Focus Group Discussion Guide**

- Are there any changes or additional questions you would suggest for this interview guide? [Asked after re-iterating each question]

Preamble: Thank you for engaging in this discussion about research, and the idea of ‘allyship’ between self-advocates and researchers. Allyship can be thought of as trying to develop a relationship between two groups of people that is more than just a formal partnership and may be perceived as more meaningful and authentic in mutual sharing. One type of research relationship that may be seen as not having characteristics of allyship is: an individual is recruited for a study, participates in an interview and later on the study is published in an academic journal. A study that could be seen as having characteristics of allyship could be: individuals and researchers speak together about priorities and a research proposal is developed, followed by group work and the collaboration of a project to share the findings. I will be asking questions about how research relationships can develop or become partnerships or allyship.

### **Questions**

1. What could authentic self-advocate or partnership engagement in research look like?

Probe: What are examples of authentic partnership/allyship

2. In your experience, does partnership in research between self-advocates and researchers exist? What makes it that way?

3. What, if any, may be the benefits of authentic partnership or allyship in research?

4. What are challenges or barriers to partnership or allyship between researchers and self-advocates?

5. Towards partnership or allyship across the broad range of people on the autism spectrum, are there other areas of diversity that should be considered?

Probe: Non-verbal and minimally verbal presentation, gender diversity, religion, cultural diversity, power differences

6. What supports, if any, are already in place for partnership to occur?

7. What additional or different supports potentially are needed for allyship to occur?

8. How might researchers and/or self-advocates go about strengthening these partnerships/research relationships?

Probe: How can these partnerships become more like allyship? Is this desired?

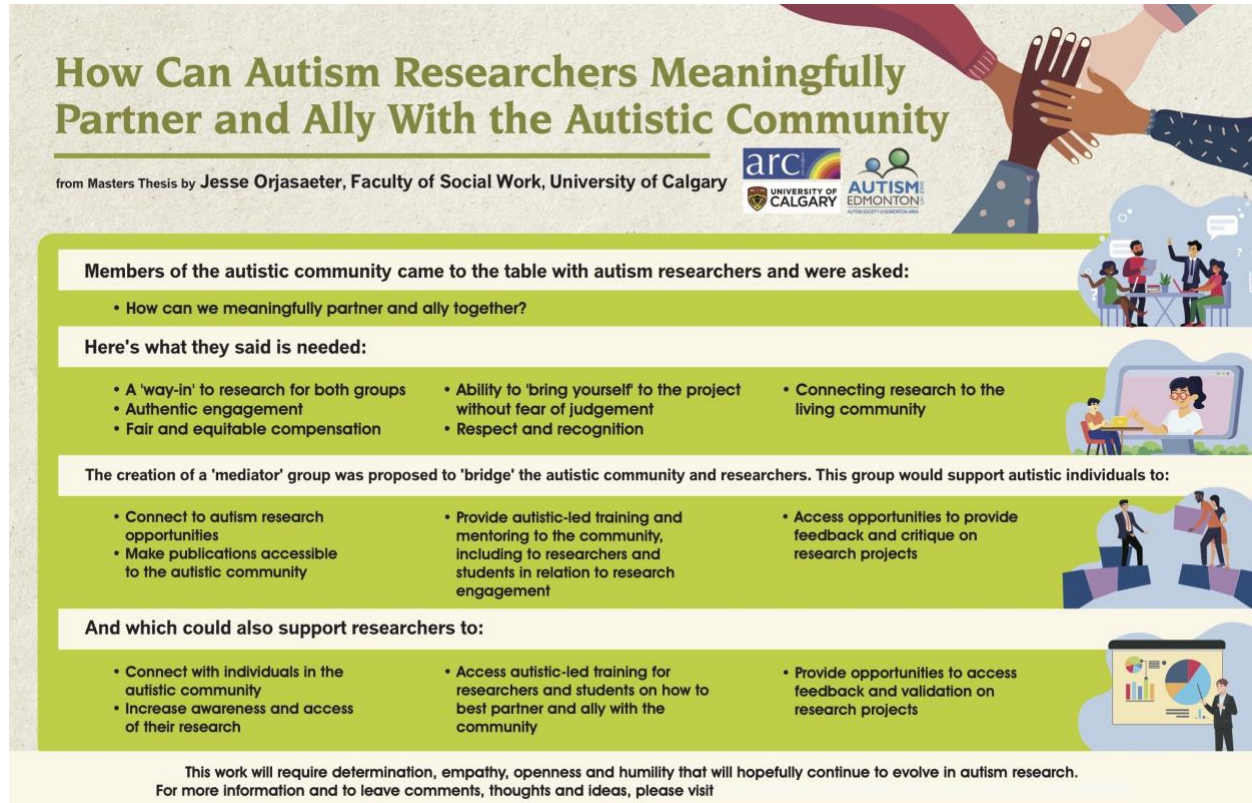
## **Appendix D: Member Checking Email**

Preamble: Thank you for participating in the recent focus group regarding allyship between researchers and self-advocates. Allyship involves meaningful partnership and mutual engagement between researchers and self-advocates. Reflecting on your participation, please consider the following questions:

1. How satisfying or not satisfying was your experience participating in the focus group and/or feedback session? Please describe.
2. How, if at all, did participation in the focus group and/or feedback session reflect principles of allyship?
3. What, if anything, would have made the focus group and/or feedback session process more reflective of principles of allyship?
4. Here are some of the general themes and ideas that came from the earlier conversations, \_\_\_\_\_ . Is there anything missing? Anything you would like to add, remove, or change?
5. How can we use this information to move forward? What happens next with this information?

Thank you for your participation.

## Appendix E: Knowledge Mobilization Poster



**How Can Autism Researchers Meaningfully Partner and Ally With the Autistic Community**

from Masters Thesis by Jesse Orjasaeter, Faculty of Social Work, University of Calgary

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**Members of the autistic community came to the table with autism researchers and were asked:**

- How can we meaningfully partner and ally together?

**Here's what they said is needed:**

- A 'way-in' to research for both groups
- Authentic engagement
- Fair and equitable compensation
- Ability to 'bring yourself' to the project without fear of judgement
- Respect and recognition
- Connecting research to the living community

**The creation of a 'mediator' group was proposed to 'bridge' the autistic community and researchers. This group would support autistic individuals to:**

- Connect to autism research opportunities
- Make publications accessible to the autistic community
- Provide autistic-led training and mentoring to the community, including to researchers and students in relation to research engagement
- Access opportunities to provide feedback and critique on research projects

**And which could also support researchers to:**

- Connect with individuals in the autistic community
- Increase awareness and access of their research
- Access autistic-led training for researchers and students on how to best partner and ally with the community
- Provide opportunities to access feedback and validation on research projects

This work will require determination, empathy, openness and humility that will hopefully continue to evolve in autism research. For more information and to leave comments, thoughts and ideas, please visit