CANADIAN JOURNAL OF
Disability Studies
Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

Canadian Journal of Disability Studies

Published by the Canadian Disability Studies Association
Association canadienne d'études sur le handicap

Hosted by The University of Waterloo

www.cjds.uwaterloo.ca

Introducing critical autism studies (CAS) from Anglophone research

Marie-Eve Lefebvre, Ph. D. candidate
Department of Psychopedagogy and Andragogy, University of Montréal
marie-eve.lefebvre.9@umontreal.ca

Nick Chown, Ph. D., M. A.
Independent scholar, Birmingham, United Kingdom
npchown@gmail.com

Nicola Martin, Ph. D.
Professor of Social Justice and Inclusive Education
London South Bank University, London, United Kingdom
martinn4@lsbu.ac.uk

Abstract

Within the historic context of a distinct lack of autistic people's representation in research, a body of emancipatory research is emerging under the banner of critical autism studies (CAS). The focus of CAS is the co-creation of scientific knowledge to produce research by and for the autistic community. Most CAS research emanates from the United Kingdom and Australia (e.g., Chown *et al.*, 2017; Pellicano *et al.*, 2014), with little present within Francophone academia in French as emancipatory design in disability research has only emerged since the 2010s. This paper aims to introduce CAS from the Anglophone academia to a Francophone audience.

We begin by stating the fundamental principles of the neurodiversity movement in which CAS has taken root (Chamak, 2010; *et al.;* Nicolaidis, 2012). Next, we contrast the predominant medical model with the social model of disability (Chamak, 2010, Rosqvist *et al.*, 2020). We then discuss CAS principles such as acknowledgement of power imbalances, recognition of autistic people's meaningful input to research, and inclusiveness through adapting the research environment (Waltz 2009; Fletcher-Watson *et al.* 2019; Pickard *et al.*, 2021; Rosqvist *et al.*, 2019). We consider potential obstacles to CAS within the academic culture, such as lack of trusting relationships, practical and systemic barriers, and limited investment to support collaborative research (Pickard *et al.*, 2021; Rosqvist *et al.*, 2019).

This paper concludes by discussing the need for a change in the language used to refer to autism (Fletcher-Watson *et al.*, 2019; Woods, 2017) and environmental modifications to facilitate fair and socially just inclusion of neurodivergent people (Fletcher-Watson *et al.*, 2019), within research and within wider society.

Keywords

Autism; emancipatory research; collaborative research; critical studies; neurodiversity

Introduction

With the growth of the neurodiversity movement since the 1990s by Australian sociologist Judy Singer, the autistic community has been more and more critical of their frequent exclusion from participation in autism research, which tends to focus on the people surrounding them, such as family and professionals mainly from medical and educational backgrounds (Wehman *et al*., 2014). In reaction to growing critiques of this situation, an emerging body of emancipatory research originally from the United Kingdom, called critical autism studies (CAS) by Davidson and Orsini (2010, cited in O'Dell *et al.*, 2016), is developing. CAS focuses on co-creating scientific knowledge *with* the autistic community and comes mainly from the United Kingdom and Australia (e.g., Chown *et al.*, 2017; Fletcher-Watson *et al.*, 2019; Pellicano *et al.*, 2014). Fewer CAS studies originate in the United States (e.g., Gillespie-Lynch *et al.*, 2017) and very few come from French-speaking academia in French (aside from Chamak, 2010).

CAS is located within the wider interdisciplinary field of critical disability studies (CDS). Goodley and his colleagues specify that "the word 'critical' denotes a qualitative shift in studies of disability from the established to the new; from the orthodox to the evolving; from the specific to the expansive'' (p. 976). Those authors would characterize the latter as research acknowledging the precarious situations and oppressions lived by disabled people who are living with sensory, physical and cognitive impairments. Additionally, CDS is interested in innovative politics, arts, scholarship and culture that offer new ways of understanding and living life, existing with one another and recreating communities that include, augment and emphasize the qualities we all hold as human beings (Goodley *et al*., 2019).

Within this wider field, O’Dell and her colleagues (2016) argue that CAS adopts similar approaches to CDS while being solely focused on autism rather than disabilities in general. These approaches are built upon, as Fine (2019) mentions, the need to “centre the experience of the person with a disability” and [… examine] disability as a social, cultural, and political phenomenon (p. 973). In CAS, this emerging body of research challenges the conception of autism as a disability although many autistic scholars consider autism as a natural human difference and adopt a neurodiversity perspective. As written by Fine (2019), it echoes disability/critical scholars Biklen (2005, cited by Fine, 2019) and Hahn (1988, cited by Fine, 2019), who both contest non-disabled research constructs of disability, such as the criteria for diagnosis or research *on* disabled communities rather than *with* them. Rather, these authors value social participation, which relates to the adequacy between an individual's characteristics (such as their identity, their aptitudes, and their limitations) and the environment’s (such as availability of support measures, support staff, and simplified documents in accessible terms), as proposed by Fougeyrollas (2010).

The lack of research in French on CAS reflects the development of CDS within this context. Although critical theories are well documented in disability studies, it is important to note that, within French-speaking contexts, such discipline is unfortunately not greatly recognized (Fougeyrollas, 2010; Parent, 2017) and is often categorized under the umbrella term “transdisciplinary.” Furthermore, comparison of English-speaking and French-speaking articles on disability is inevitably unequal given the preponderance of publications in English. Specifically, the emergence of a critical body of studies remained mostly English-speaking until just over a decade ago when Fougeyrollas (2010) released the HDM-DCP 2, a social model of disability that has been widely accepted throughout literature in French.[1]

As is true for other subjects studied by Francophone researchers, anglophone research is predominant. As argued by Imbeau and Ouimet (2013), publishing articles in English appears to have advantages such as accessibility by bilingual Canadian researchers. Considering this context, the comparison between the state of the literature in English and French is uneven due to marked linguistic differences.

Although there is an emerging body of CAS literature within autism research in English, "critical autism studies" has yet to feature within research in French. Often combined with research on intellectual disability, some collaborative and participatory methods are being mobilized without referring explicitly to critical studies of disability, but these remain emergent and marginal as they were mainly introduced in the early 2010s in autism research in French (Petitpierre et Martini-Willemin, 2014; Parent, 2017). This overview is not very representative of autism, specifically for autistic people without intellectual disabilities. However, these methods have remained very marginal and emerging in autism research since the 2010s (Parent, 2017). It is difficult to qualify or quantify critical disability more broadly within Francophone research.

All things considered, given that most autism research in French has focused on autistic children, the recent use of emancipatory and participatory designs could have been more difficult to put into practice. Emancipatory and participatory designs are more time consuming than traditional designs,

---

[1] From Fougeyrollas' social model (2010), a shift of language can be identified in several governmental and community official documentation, referring now to « personne en situation de handicap» (''person in a disabling situation''; within a social perspective, that is a disability resulting from the lack of accommodations for an individual in an environment) rather than «personne handicapée» (''disabled person''; within a medical perspective, as someone who is disabled regardless of the presence of accommodations..

given the need to obtain informed consent for instance (Rosqvist *et al.*, 2020). By considering the differences between disability and critical literature in English and in French, this article aims to introduce CAS in Francophone research contexts that echo emancipatory methods.

Throughout this text, we aim to highlight the importance of mobilizing the expertise of autistic people that they developed throughout their lived experience as well as to close the gap between literature in French and critical methodology which requires research to be “by and for” autistic people. This introduction begins by creating bridges between CAS and disability studies as we consider the neurodiversity movement and consider tensions between medical and social model thinking about disability (O’Dell *et al.*, 2016), and their implications for autism scholarship. As well as considering the principles underpinning CAS, we reflect on potential obstacles to their realization within academic culture and propose guidelines for future autism research that places autistic participation at the centre rather than viewing autistic experience through non-autistic eyes. As we progress through this article, we identify some factors associated with research in French that might explain the underdevelopment of CAS and CDS in general in Francophone academia.

1. Fundamentals of the neurodiversity movement in the community

The neurodiversity movement is located within the neurodivergent community, which includes autistic people, and those identified and identifying with diagnostic labels such as attention deficit disorder (ADD), dyslexia, dyspraxia and so on. The term “neurodiversity” was brought to wider attention by sociologist Judy Singer during the 1990s when she was advocating for her autistic daughter. It was then adopted by other parents through community-driven support groups (Chamak, 2010, Rosqvist *et al.*, 2020).

As neurodiversity was increasingly adopted within the community, a movement formed around this concept to redefine disability. A key assumption of this movement is that all forms of neurological diversity are valuable and that such diversity should be understood and respected as a natural neurodevelopmental outcome. In other words, neurodiversity is a form of diversity which sits alongside cultural, gender, sexual, physical and other diversities.

At the heart of the movement, neurodiversity advocates (including autistic people, families, medical professionals and researchers aligned with the neurodiversity movement) can positively impact how autism is understood through a non-medicalized lens. For autistic people, considering autism as a difference rather than a disability can potentially increase their self-confidence and enable self-advocacy within social environments created by non-autistic people (Gillespie-Lynch *et al.*, 2017; Pellicano *et al.*, 2021; Woods, 2017). By redefining their disability, endorsing neurodiversity often leads to an autistic person positively reinterpreting the diagnostic criteria for autism (Jones *et al.*, 2014).

Since the first usage of the term in the 1990s, interest towards the neurodiversity movement has become increasingly prominent through online support groups and forums. The Internet could be described as "to autistic people what sign language is to deaf people in that Internet forums and discussions facilitate communication between [autistic] people […] and allow them to be less isolated" (p. 1, Dekker, 1999). These online platforms appear to be more accessible for autistic people as the social environment is potentially more predictable than with face-to-face interaction, and information is more organized online.

This means that topics of interest can be easily pursued, and more individuals can interact independently of their situation, education, family environment, lifestyle, and localization in the world. A study of French-Canadian online platforms by Nugent (2017 identified that autistic people wanted to create autistic Internet communities to facilitate self-expression and social integration among autistic people which reflected the aims of the neurodiversity movement without those involved in the communities having prior knowledge of this newer conception of disability.

Beyond community-based support groups, neurodiversity-informed research-led groups are emerging, including Spectrum Partnership in Research and Education (AASPIRE), the Participatory Autism Research Collective (PARC), the Independent Autism Research Group, and the Insight Group, formed by Autistica. The creation of those online groups (some of which also involve interaction offline) aims to establish a dialogue between autism researchers through sporadic meetings, where members can present their projects, and to promote collaboration amongst autistic participants. It should be noted that there are secret Facebook groups[2] of English-speaking autistic autism researchers (one of which was founded by the second author, Nick Chown) with about 3,500 members.

Across Francophone regions, those initiatives are unfortunately not well documented. To our knowledge, no equivalent exists to the English community-based support groups cited above, which could be partially due to the lack of knowledge about neurodiversity in Francophone contexts. Aside from Brigitte Chamak (2010), a French sociologist who published a few papers on the topic, we identify that the number of published manuscripts, since 2010, across the most used databases for documents in French (Google Scholar, ERIC, Érudit, Web of Science) is only 8 documents. Nonetheless, several French-community support groups are present, specifically on

---

[2] The Facebook groups of autistic autism researchers are both secret groups because of the stigma still attached to autism which means that to disclose being autistic risks damage to an individual's academic career.

social media like Facebook (e.g., Ressources et soutien autisme; Aspie Québec; Autisme, vivre avec).

We hypothesized that, as with English-speaking scientific literature, the Francophone autistic community could be developing a neurodiversity movement that has yet to be documented by the scientific literature in French. Especially strong within the autistic community, the neurodiversity movement can be situated in parallel to the social model of disability (den Houting, 2019), and critical disability studies (Goodley *et al*., 2019). This is explained and contrasted with medical model thinking in the following section.

2. Social model of disability and medical model of disability in autism research

Understanding the concept of disability is important in order to make sense of autism research – and the social and medical models of disability are most pertinent (O'Dell *et al.*, 2016). Neurodiversity, in tune with the social model, emphasizes the lack of inclusiveness in environments that create disability for people with impairments. The social model challenges the medical model, which promotes the reduction of autistic traits to conform to a flawed notion of "the norm" through intervention and medication (Chamak, 2010, Rosqvist *et al.*, 2020).

Social modelists, such as Fougeyrollas (2010) who is highly cited in the literature on disability in French, argue that environments are usually not adapted to disabled people, which causes their exclusion, whereas from the medical model's standpoint, disabled people are not adapted to their environments, and they need to adapt to be included rather than the opposite. Researchers, such as Nicolaidis (2012) and others, argue that while autistic people experience impairment-related challenges, societal structures do much to exacerbate these and therefore create their disability. Several theoretical research models were inspired by the social model to explain more precisely how disability is experienced. Examples include the Nordic relational models; in Canada, the Human Development Model—Disability Creation Process 2 [HDM-DCP 2] and Fougeyrollas (2010); digital accessibility pyramid for autistic users (Lussier-Desrochers *et al.*, 2016.)

Although most CAS output is English-speaking, Fougeyrollas (2010) released the HDM-DCP 2, a revised version of the original model conceptualized in 1995, a social model of disability that has been widely accepted throughout Francophone academia. Because this model proposed a new terminology to refer to disabled people (that is "personne en situation de handicap"), the concept of disability arising from an incompatible environment rather than being inherent in an individual was introduced within Francophone contexts. Within the following years in Canada, several government documents and community services used that idiom to refer to disabled people in a positive manner (Office de personnes handicappées du Québec [OPHQ], 2019). This appears to have been the trigger for the development of support groups for disabled people and, therefore, autistic people as well, as a social model perspective on disability began to take hold.

The philosophy under the social model is nonetheless lacking several sources on autistic people. In most research papers, government documents or in the media, the autism discourse is dominated by medicalized concepts of autism as a disorder and deficits requiring "fixing," "treating" and "erasing," which resonate highly with current Francophone literature on autism. Pellicano and her colleagues (2014) demonstrate that the stigma associated with autism is perpetuated through the usage of stigmatizing language to refer to autism is perpetuated in communities and the media (including newspapers, social media, television, shows and movies) and this impacts the daily activities of autistic adults. In addition, stereotypes and common perceptions are reinforced by, for example, autistic individuals being compared to Rain Man (there could hardly be a less typical autistic person) and other unrealistic or stereotypical autistic characters in movies or shows. Expressions that have no theoretical basis such as "we're all a bit autistic" are all too common and serve to minimize the struggles many autistic people encounter in daily life.

Within Francophone literature on autism, Laflamme (2020) identifies several pejorative terms or idioms often used, inside and outside academia, to refer to autistic people as if they were living with an illness, such as "people with autism," "people living with autism," "people suffering from autism," and "people infected with autism." As pointed out by Pellicano and her colleagues (2014), medical and pejorative language used to talk about autism arguably marginalizes autistic people and adds to their challenges.

Increasingly, autistic people and their allies are questioning this general medicalized discourse about autism, and the growing influence of the neurodiversity movement is highlighting social model responses based on a rights-based agenda around entitlement to social inclusion. CAS, which is aligned with the social model and CDS, is becoming increasingly influential and underpins important developments such as those enabling autistic people to have greater control of their lives which has the potential to reduce the adverse impacts on their mental health damage through having to adapt to the demands of neurotypical society (Woods, 2017).

3. Emerging body of critical autism studies (CAS)

The inclusion of autistic perspectives in research still tends to be the exception rather than the rule (Chown *et al.*, 2017). CAS could be defined as a counterpoint to predominantly medicalized autism research which de-emphasizes autistic involvement and is arguably disconnected from the needs of the autistic community (den Houting & Pellicano, 2019; Pellicano *et al.*, 2014).

Without their active participation in research about them, the autistic community has been critical of autism research that is seemingly guided by the interests of (usually non-autistic) researchers and funders with a lack of involvement from the autistic community (Pellicano *et al.*, 2014). The lack of research by and for autistic people appears to contribute to the gaps between autistic and non-autistic communities. On that topic, Milton (2012) developed the double empathy hypothesis when discussing the problem of mutual incomprehension between autistic and non-autistic people. Indeed, this theory refers to the different experiences, also called “double”, of the same situation. The gap between autistic people's and ballistic people's perspectives would explain the difficulty in understanding each other. This author suggested that greater involvement of autistic researchers in autism research could go some way to addressing this concern.

Other worries can be noted by both researchers in CAS and the autistic communities. On one hand, Howlin and Magiati (2017) suggest that the contributions of research to the quality of life of autistic people could well be marginal if autistic people are not active contributors and do not identify with the purpose, approach or findings of the research. On the other hand, some families, educators, and clinicians working with autistic people have expressed the concern that autism research generally fails to describe the nature of autistic life experiences (Jones *et al.*, 2014; Nicolaidis, 2012). From both these perspectives, we could then question the relevance of those studies which appear to be disconnected from the realities of autistic people.

To promote and facilitate research projects with autistic people, more researchers advocate for emancipatory and participatory inclusive principles and practices within CAS research

(Fletcher-Watson *et al.*, 2019; Milton, 2014; Nicolaidis *et al.*, 2011). This emergence of this collective awareness leads, specifically within autism research, to an academic field called CAS, as discussed in the following section.

3.1 Principles of CAS

CAS principles chime with emancipatory principles, acknowledge the power imbalance between researchers and participants, and recognize the meaningful input of autistic people into research and the necessity for inclusiveness by adapting the research environment (Fletcher-Watson *et al.*, 2019; Waltz 2009). Echoing feminist, queer theory and the concept of intersectionality, and similar to critical disability studies (Goodley *et al., 2019*), academia can offer a site in which autistic experiences can challenge the norm and call power into question (Rosqvist *et al.*, 2019). True emancipatory CAS would include leadership by autistic researchers, co-creation partnerships, engagement with the autistic community (e.g., via social media) and consultation with relevant individuals or community organizations.

To transform the traditional dynamic between researchers and autistic participants, CAS aims to provide a safe environment in which to explore issues of self-expression, identity, and share personal experiences (Chown *et al.*, 2017; O'Dell *et al.*, 2016). This involves ensuring that the authentic views of participants are captured and reported, and that the research leads to beneficial outcomes for stakeholders (Waltz, 2006). In addition, this involves using emancipatory methods, namely to encourage the participation of co-researchers and lead them to have control in the research, to contribute to decision-making within the research process (Zarb, 1992, pp. 125-126), and to clarify the decision-makers' power over research. This dynamic reveals how co-researchers make decisions throughout the research, including their influence on the data, their analysis, and their presentation. In other words, the distribution of power in research is highlighted by striving to share it with co-researchers from an emancipatory perspective.

In practice, adapting the research environment is relevant to researchers and participants at all stages of the research process, including during data collection and knowledge transfer back into the community. Transforming the power dynamic involves researchers being flexible to enable the productive employment of autistic researchers and the capturing of diverse perspectives based on the communication styles of participants. Often nonspeaking autistic people and those with additional intellectual disabilities are excluded (Pickard *et al.*, 2021; Rosqvist *et al.*, 2019). Creative and visual methods of data collection may be appropriate and adapting the physical research environment to reduce sensory concerns and distractions may be necessary (Rosqvist *et al.*, 2019). Indeed, Rosqvist and colleagues (2019) propose to communicate accessibly such as through visual means, lay summaries, video, performance, and easy-read versions.

When discussing the value autistic researchers brought to a project which involved autistic participants recounting their life history, and regardless of the challenges, Pellicano and colleagues (2021) encouraged creating more of these research opportunities. The autistic participants reported feeling “supported all the way” and agreed, “it was made easier because I had an autistic researcher interviewing me” (p. 1). They also felt that they could share more with an autistic person (Pellicano *et al.*, 2021). Similarly, Damian Milton, was the lead researcher of a study by Martin and colleagues (2019). He spoke in this role to parents of autistic children, many of whom reported that he was the first autistic adult they had been able to talk to in this way and that the experience was “transformational.” Milton (2014) argues that autism research cannot achieve ethical or epistemological integrity without the involvement of autistic researchers.

This point is well illustrated in studies by Pellicano *et al.* (2014) and Martin *et al.* (2019), as in both cases, the involvement of autistic researchers made a valuable difference to the experience of the autistic participants. On that topic, Milton and Bracher (2013) were among the first influential voices on the potential to enrich autism research through autistic involvement by increasing epistemological integrity and aligning with the lived experience and priorities of autistic people. Autistic community involvement builds upon unique insights which can heighten scientific knowledge about autism (Gillespie-Lynch *et al.*, 2017).

Within French-speaking literature, there are few ‘authentic’ projects. Examples of such projects are the long-term collaboration between Laurent Mottron and Michelle Dawson and the ongoing project of autistic mentoring by autistic people, led by the *Autisme Ensemble* (Centre hospitalier universitaire Sainte-Justine). As observed by Parent (2017), the underdevelopment of literature in French more broadly could partially explain this. As is true for other subjects studied by Francophone researchers, English-speaking research is predominant and, as argued by Imbeau and Ouimet (2013), publishing articles in English appears to have more benefits for researchers, especially as regards accessibility for Canadian researchers. Benefits include more opportunities to publish, to be cited, to present around the world, and to have access to international recognition or prizes.

Consequently, a great majority of research that could be published in French is published in English instead. To cite Parent (2017) on this topic “As they [English-speaking researchers] are in greater number and are more involved in research regarding the rights of disabled people in the United States and the United Kingdom, their scientific knowledge can be more easily transmitted [than scientific knowledge in French]” (p. 187). It appears that a delay in the development of any specialty within academia in French is to be expected as English publications would have to be translated and reinterpreted within this specific context.

3.2 Obstacles to the development of CAS

To develop CAS research in any language requires developing trusting relationships, addressing practical requirements and finding greater investment to support collaborative research.

Milton and colleagues (2019) focus their attention on addressing obstacles to the fair employment of autistic researchers. Martin (2020) argues autistic researchers face barriers to equitable employment in academia. Martin (2020) and others remind us that the employment contracts of autistic researchers are rarely fair and equitable and highly skilled autistic researchers often find themselves being expected to provide their expertise for free. However, the academic system needs to work for autistic people more generally (Martin, 2020, Pickard *et al.*, 2021). That is, academic contexts need to support a productive dynamic between researchers and participants. Establishing a trusting relationship takes time (which may not have been factored into funding decisions), and yet the expectation is to produce scientific research papers rapidly (Pickard *et al.*, 2021). Specifically, it is necessary to build bridges through collaborative structures such as the Participatory Autism Research Collective (PARC), the National Association of Disability Practitioners (NADP), and the Journal of Interdisciplinary Practice in Further and Higher Education (JIPFHE) to enhance opportunities for autistic people, even if there are issues associated with time, funding and support. Funding could be an even greater obstacle in academia in French, as it generally has received less financial support than English scientific production (Imbeau & Ouimet, 2013).

Emancipatory research design's presence in the field of autism research is relatively new and sporadic (Milton & Bracher, 2013) and meaningful inclusion of autistic voices tend to be the exception rather than the rule (Chown *et al.*, 2017). Despite emancipatory research having a long tradition in other fields, such practices have been slow to reach the autism field (Milton & Bracher, 2013; Pickard *et al*., 2021; Woods *et al*. 2017). Within the small number of studies that claim, Jivraj and his colleagues (2014) highlighted that a smaller piece of that research actually aligns with emancipatory principles. Indeed, research is rarely truly collaborative with the aim to co-construct research knowledge with autistic people (Rosqvist *et al.*, 2019).

Pellicano and colleagues (2014) emphasize participant involvement in dissemination, dialogue and partnerships and suggest that meaningful engagement often evolves gradually. The first level is about disseminating knowledge to autistic communities in accessible ways, whether through infographics, emails or workshops. In the second level, the research teams communicate with autistic people, sometimes called "consultants," to get their point of view on the project. In the third level, research teams collaborate with people with autism as partners to decide on research goals and make decisions to achieve them during the project. Collaboration is necessary to create a dialogue between autism researchers and autistic participants and arguably autistic researchers are best placed to build the necessary bridges, as demonstrated by Pellicano *et al.* (2014) and Martin *et al.* (2019).

The research environment could offer a site in which autistic experiences can challenge norms and call into question power relations that marginalize autistic people. Rosqvist and colleagues (2019) explain that they "[…] look to academic space as a site of emancipation in itself. They consider how the creation of a neurodiverse writing collective may add nuance to existing knowledge creation" (p. 1083). Similarly, the Participatory Autism Research Collective (PARC) (Milton *et al.*, 2019) attempts to open up academic spaces to autistic researchers. We can also think about London South Bank University, where autism research takes place under the banner of the Social Justice and Global Responsibility Research Centre and, unusually, all funded autism research includes paid autistic researchers as a matter of principle. Unfortunately, such research opportunities in academia remain few and far between which forces many autistic autism researchers to undertake research on an unfunded basis in their spare time (e.g., the Independent Autism Research Group). Unfortunately, Pellicano and her colleagues (2021) noted that researchers rarely provide this level of detail, such as the length of the project, co-researchers' responsibilities, communication means or the decision-making process. Ideally, funders of autism research should require this and even make real engagement between autistic researchers and participants a condition of funding, as proposed by the Social Justice and Global Responsibility Research Centre, United Kingdom.

Rosquist (2019) discusses the need for researchers to be aligned with and able to represent the diverse standpoints of participants. Factors such as unconscious bias, internalized ableism, insider/outsider perspectives[3] and power dynamics all come into play. Language can be a site of struggles with the potential to "other" participants (and autistic researchers) through medical and deficit model terminology. The word "disorder" for example is highly problematic (Rosquist, 2019; Martin *et al.*, 2018). Medical/deficit model language is used almost exclusively in Francophone

---

[3] This theory is about members of a cultural, economic, identity, or social group who are considered insiders. People who do not belong to it are thus non-members, also called outsiders. In a research context, the insiders-outsiders theory implies that researchers who are not members of a group at the centre of their studies may have understandings and biases associated with their lack of experience in that group. For example, they might ask naïve questions, not understand the meaning or importance of certain issues raised and question the relevance of certain remarks (for more details, see Brigdes, 2017).

research which arguably adds to the distance between researchers and autistic people. This could be one of the main obstacles to Francophone CAS study as research is not seen as an emancipatory space, but rather another neurotypical environment that creates challenges for autistic people.

In other terms, non-autistic researchers might underestimate the abilities of autistic communities as they view them as “lacking ‘from the neurotypical norm. Pickard and colleagues (2021) call for investment in autistic-informed autism research which moves beyond the existing tokenistic approach.

This absence of global initiatives could partially be explained by the difficulty of carrying out collaborative research with autistic people within Francophone contexts. As we discussed previously, this could be accentuated by the limited amount of literature in French on critical disability studies (Parent, 2017), as well as collaborative methodologies with marginalized participants (Petitpierre et Martini-Willemin, 2014).

In all contexts, to explain this difficulty to transfer this inclusive methodology into autism research, we hypothesize that, because autistic people are considered within the medical model by many scholars, these scholars may believe that autistic people cannot complement current autism research literature. According to Waltz (2006), some non-autistic researchers have concerns about autistic participation in research because of potential communication challenges, especially to obtain informed consent, to avoid misinterpreting their experience, and to reduce distractions (e.g., background noise, neon light, number of speakers, lack of visual support available). On a positive note, even with the small number of actual emancipatory studies, increasingly autistic researchers and allies internationally recognize the need to adopt collaborative methodologies and co-construct knowledge with autistic people (Fletcher-Watson *et al.*, 2019; Milton, 2014; Nicolaidis *et al.*, 2011).

4 Conclusions and guidelines for autism research

CAS, rather than being a methodology or a set of methods, is a mindset and an attitude towards autistic people informed by social model thinking and the neurodiversity paradigm. Unfortunately, CAS has yet to feature in Francophone research, even if some social disability models have been established for several years. In this article, we pointed out that language specifically used within research in French illustrated that the influence of the medical/deficit model of disability is still strong. In contrast, social model thinking encourages research based on an understanding that most environments are not inclusive for neurodivergent people, and it is the environment that needs to change rather than the individual. Pellicano and colleagues (2014) advocate for addressing negative discourses around autism and the potential of social model thinking in this regard. Medical/deficit model language, used almost exclusively in Francophone research, arguably adds to the distance between researchers and autistic people, which could be one of the main obstacles to CAS study as research is not seen as an emancipatory space, but rather another neurotypical environment that creates challenges for autistic people. Beyond those obstacles, autism research informed by autistic people has much to contribute to shifting the burden of adaptation away from autistic individuals onto neurotypical environments (Woods, 2017). This applies as much to Francophone societies as Anglophone societies.

Research has a role to play in this endeavour. The goal of co-creation of research knowledge on neurodiversity involves more than the inclusion of neurodivergent participants, but academia as a whole presents myriad obstacles to the fair employment of neurodivergent researchers, especially autistic researchers (Chown *et al.*, 2015; Martin, 2020).

Moving beyond the tokenistic must be based on creating trusting relationships between researchers and participants, which can be created through an emancipatory research environment adapted to the characteristics of neurodivergent people. In autism research in French, some collaborative and participatory methods remain emergent and marginal as they were mainly introduced in the 2010s (Petitpierre & Martini-Willemin, 2014). It may be that the work of autistic scholars is now influencing positive change in this regard (Milton *et al.*, 2019).

Fletcher-Watson and colleagues (2019) suggest that the transition towards adapting the research environment often involves simple environmental modifications that could facilitate the inclusion of all neurodivergent people, both in and outside of research. These include modifying physical spaces and bureaucracy, removing unnecessary stimuli, such as neon lights and crowded furniture and aiming for quieter and noise-reduced ambiance. Several resources are available that address accessibility to promote neurodivergent participation (see AASPIRE[4]; Fletcher-Watson *et al.*, 2019; Nicolaidis, 2012; Nicolaidis *et al.*, 2011; PARC[5]; Pellicano *et al.*, 2014, 2021). Members of the Participatory Autism Research Collective (PARC) have commented on the value of online engagement in this regard (Milton *et al.*, 2019).

Having autistic researchers at the heart of autism research is the ideal. Chown and colleagues (2017) proposed that one or more autistic researchers should validate the identification and definition of autism research projects as:

---

[4] https://aaspire.org
[5] https://participatoryautismresearch.wordpress.com

> this ensures that the project is based on a belief that the main reasons for autistic people not being able to live a fulfilling life are the barriers placed in their way by a non-autistic society, and that it is a societal responsibility to remove these barriers, not blame the difficulties faced by autistic people on them as individuals (p. 727).

This citation echoes social model thinking which aims to achieve a shift towards collective responsibility to create more inclusive research. Potentially, this could change the current academic culture towards the inclusion of neurodivergent researchers as well as nurture projects that aim to address disabling barriers.

Emancipatory research and community-led online groups are burgeoning internationally, especially as a result of the pandemic which forced interaction to go online. Examples include the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), the Participatory Autism Research Collective (PARC), the Insight Group, formed by Autistica, and the Independent Autism Research Group. Through these initiatives, growing numbers of autism researchers can present their projects and get inspired by their colleagues, which promotes further collaboration with autistic participants. In Francophone regions like Canada, France, Sweden, Belgium, and the Francophone communities in Africa and Asia, such emancipatory groups are rare. This paper aims to stimulate further progress towards inclusive autism research informed and co-produced by autistic people with the aim of addressing the socially constructed disabling barriers experienced by autistic people.

References

Bridges, David. (2017). 'Nothing about us without us': The ethics of outsider research. In D. Bridges (eds.), *Philosophy in educational research* (pp. 341-361). Springer.

Chamak, B. (2010). Autisme, handicap et mouvements sociaux. *Revue Européenne de Recherche sur le Handicap*, *4*(2), 103-115.

Chown, N. (2019). Who benefits from autism research? And to what extent is it participatory and/or emancipatory? A brief follow-up to Pellicano, Dinsmore and Charman (2014). *Autism Policy & Practice*, *2*(1). 1-14.

Chown, N., Beardon, L., Martin, N. & Ellis, S. (2015). Examining intellectual ability, not social prowess: removing barriers from the doctoral viva for autistic candidates. *Autism, Policy & Practice*, *1*(2),

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L. & MacGregor, D. (2017). Improving research about us, with us: A draft framework for inclusive autism research. *Disability & Society*, *32*(5), 720-734.

Dekker, M. (1999). *On our own terms: Emerging autistic culture.* Autscape. http://www.autscape.org/2015/programme/handouts/Autistic-Culture-07-Oct-1999.pdf

den Houting, J., & Pellicano, E. (2019). A portfolio analysis of autism research funding in Australia, 2008–2017. *Journal of Autism and Developmental Disorders*, *49*(11), 4400–4408. https://doi.org/10.1007/s10803-019-04155-1

Fine, M. (2019). Critical disability studies: Looking back and forward. *Journal of Social Issues*, 75(3), 972-984. http://doi.org/110.1111/josi.12344

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, *23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Fougeyrollas. (2010). *La funambule, le fil et la toile.* Presses de l'Université Laval.

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology*, *8* (438). https://doi.org/10.3389/fpsyg.2017.00438

Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society, 34*(6), 972-997. https://doi.org/10.1080/09687599.2019.1566889

Howlin, P., & Magiati I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry*, *30*(2), 69–76.

Imbeau, L. M. & Ouimet, M. (2013). Langue de publication et performance en recherche : publier en français a-t-il un impact sur les performances bibliométriques des chercheurs francophones en science politique ? *Politique et Sociétés, 31*(3), 39–65. https://doi.org/10.7202/1014959ar

Jivraj, J., Sacrey, L. A., Newton, A., Nicholas, D., & Zwaigenbaum, L. (2014). Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism*, *18*(7), 782–793. https://doi.org/10.1177/1362361314539858

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom. *Journal of Autism and Developmental Disorders*, *44*, 3033–3044. https://doi.org/10.1007/s10803-014–21613

Laflamme, M. (2020). *Reconstructions identitaires chez les femmes autistes diagnostiquées à l'âge adulte* [Doctoral thesis, Université de Montréal]. Papyrus. https://papyrus.bib.umontreal.ca/xmlui/bitstream/handle/1866/25164/Laflamme_Maude_2020_memoire.pdf?sequence=2&isAllowed=y

Lussier-Desrochers, D., Normand, C., Fecteau, S., Roux, J., Godin-Tremblay, V., Dupont, M.-È., Caouette, M., Romero-Torres, A., Viau-Quesnel, C., Lachapelle, Y., & Pépin-Beauchesne, L. (2016). Modélisation soutenant l'inclusion numérique des personnes présentant une DI ou un TSA. *Revue francophone de la déficience intellectuelle, 27*, 5-24. https://doi.org/10.7202/1039012ar

Martin, N. (2020) University through the eyes of autistic students and staff. In D. Milton (eds.), *Neurodiversity reader: Exploring concepts, lived experience and implications for practice* (pp. 287 – 308). Pavilion.

Milton, D. E. (2012). On the ontological status of autism: The "double empathy problem. *Disability Society*, *27*, 883–887.

Milton, D. E. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, *18*(7), 794–802.

Milton, D. E., & M. Bracher. (2013). Autistics speak but are they heard? *Journal of the BSA MedSoc Group*, *7*, 61–69.

Milton, D., Ridout, S., Kourti, M., Loomes, G., & Martin, N. (2019). A critical reflection on the development of the Participatory Autism Research Collective (PARC). *Tizard Learning Disability Review*, *24*(1), 82–89

Nicolaidis, C. (2012). What can physicians learn from the neurodiversity movement? *Virtual Mentor*, *14*(1), 503–510. https://doi.org/10.1001/virtualmentor.2012.14.6.oped1-1206

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Ashkenazy, E., Boisclair, C., Robertson, S., & Baggs, A. (2011). Collaboration strategies in nontraditional community-based participatory research partnerships: Lessons from an academic−community partnership with autistic self-advocates. *Progress in Community Health Partnerships: Research, Education, and Action*, *5*(2), 143–150. https://doi.org/10.1353/cpr.2011.0022

Nugent, B. (2017). Voies | Voix autistes franco-ontariennes : quand la reconnaissance de la neurodiversité devient-elle une voie émancipatrice militante? *Reflets*, *23*(2), 32-68. https://doi.org/10.7202/1043302ar

O’Dell, L., Bertilsdotter Rosqvist, H., Ortega, F., Brownlow, C., & Orsini, M. (2016). Critical autism studies: exploring epistemic dialogues and intersections, challenging dominant understandings of autism. *Disability & Society*, *31*(2), 166-179.

Office des personnes handicappées du Québec (OPHQ). (2019*). Personne handicapée ou personne en situation de handicap, y a-t-il une difference?* https://www.ophq.gouv.qc.ca/publications/cyberbulletins-de-loffice/express-o/volume-13-

numero-4-ete-2019/mieux-comprendre/personne-handicapee-ou-personne-en-situation-de-handicap-y-a-t-il-une-difference.html#:~:text=L'article%201%20d%C3%A9finit%20ainsi,accomplissement%20d'activit%C3%A9s%20courantes%20%C2%BB.

Parent, L. (2017). Ableism/disablism, on dit ça comment en français*? Canadian Journal of Disability Studies*, *6*(2), 183–212. https://doi.org/10.15353/cjds.v6i2.355

Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on researcher-community engagement in autism research in the United Kingdom: A mixed-method study. *PLOS ONE*, *9*(10), Article e109946. https://doi.org/10.1371/journal.pone.0109946

Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Heyworth, M., Clapham, H., & Yudell, M. (2021). 'I knew she'd get it and get me': Participants' perspectives of a participatory autism research project. *Autism in Adulthood*. https://doi.org/10.1089/aut.2021.0039

Petitpierre, G. V., & Martini-Willemin, B.-M. (2014). *Méthodes de recherche dans le champ de la déficience intellectuelle : nouvelles postures et nouvelles modalités*. Peter Lang. https://doi.org/10.3726/978-3-0352-0252-6

Pickard, H., Pellicano, E., den Houting, J., & Crane, L. (2021). Participatory autism research: Early career and established researchers' views and experiences. *Autism*. https://doi.org/10.1177/13623613211019594

Rosqvist, H. B., Chown, N., & Stenning, A. (2020). *Neurodiversity studies: A new critical paradigm*. Routledge.

Rosqvist, H. B., Kourti, M., Jackson-Perry, D., Brownlow, C., Fletcher, K., Bendelman, D., & O'Dell, L. (2019). Doing it differently: Emancipatory autism studies within a neurodiverse academic space. *Disability & Society, 34*(1),7–8, 1082–1101. https://doi.org/10.1080/09687599.2019.1603102

Waltz, M. (2006). *Participatory and Emancipatory Autism Research: What's the Problem?* Autism 2009 Virtual Conference. Wehman, P., Schall, C., Carr, S., Targett, P., West, M., & Cifu, G. (2014). Transition From school to adulthood for youth with autism spectrum disorder. *Journal of Disability Policy Studies, 25*(1), 30–40. https://doi.org/10.1177/1044207313518071

Wilson, L. & Martin, N. (2017). Disabled student support for England in 2017. How did we get here and where are we going? A brief history, commentary on current context and reflection on possible future directions. *Journal of Inclusive Practice in Further and Higher Education*, *9*(1).

Woods, R. (2017). Exploring how the social model of disability can be reinvigorated for autism: In response to Jonathan Levitt. *Disability & Society*, *32*(7), 1090–1095. https://doi.org/10.1080/09687599.2017.1328157

Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of Disability research production. Disability, *Handicap & Society*, *7*(2), 125-138. https://doi.org/10.1080/02674649266780161