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## **Le mouvement de la neurodiversité :**

***Pourquoi a-t-il émergé dans les communautés de l'autisme, mais pas dans les communautés de troubles cognitifs légers ?***

### ***The Neurodiversity Movement:***

***Why did it emerge in Autism Communities, though not in Mild Cognitive Impairment Communities?***

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### **RÉSUMÉ**

Le mouvement de la neurodiversité et l'autisme, dont le mouvement est issu, font tous deux l'objet de nombreux débats. La compréhension des enjeux passe par le dialogue. Une autre possibilité est d'explorer la neurodiversité et son mouvement. Cependant, au lieu d'articuler et de défendre des positions établies et évolutives, le mouvement de la neurodiversité pourrait être analysé pour voir s'il pourrait bénéficier à des groupes qui souffrent de handicap, par exemple dans les troubles cognitifs légers (TCL). Cet article cherche des réponses à une curieuse absence d'un mouvement de neurodiversité dans le TCL. Nous suivons la définition de la neurodiversité de Nick Walker, souvent citée : « la diversité de l'esprit humain, la variation infinie du fonctionnement neurocognitif au sein de notre espèce » (Walker, 2024). L'article pose une question théorique sur le mouvement de la neurodiversité : « Pourquoi a-t-il émergé dans les communautés autistes, mais pas dans les communautés de troubles cognitifs légers ? » Certaines réponses sont trouvées en recherchant dans la littérature les origines de la neurodiversité, puis en comparant l'histoire avec les études sur le TCL et les circonstances et les expériences des personnes atteintes de TCL. L'article commence par examiner la neurodiversité, son paradigme et son mouvement. Ensuite, nous considérons le TCL comme une affection neurologique qui semble être un candidat approprié pour la « neurodiversité ». Après réflexion et délibération, les résultats sont cinq facteurs qui fournissent des explications crédibles de l'absence d'un mouvement de neurodiversité TCL et des raisons pour lesquelles un mouvement de neurodiversité rencontre des difficultés à s'enraciner dans les communautés TCL. Conceptuellement, la pensée de la neurodiversité n'a pas besoin d'être exclusive à l'autisme. En fait, son utilisation efficace dans la communauté de l'autisme peut être une feuille de route utile.





## **MOTS-CLÉS**

neurodiversité, mouvement de la neurodiversité, autisme, troubles cognitifs légers (TCL), plaidoyer, mouvements sociaux

## **ABSTRACT**

*The neurodiversity movement, and autism, from which the movement arose, are both subjects of much debate. Understanding the issues requires dialogue. An alternative possibility is to explore neurodiversity and its movement. However, instead of articulating and defending established and evolving positions, the neurodiversity movement could be analyzed to see if it might benefit groups which experience disability, e.g., in Mild Cognitive Impairment (MCI). This article seeks answers to a curious absence of a neurodiversity movement in MCI. We follow Nick Walker's frequently cited definition of neurodiversity: "the diversity of human minds, the infinite variation in neurocognitive functioning within our species" (Walker, 2024). The article poses a theoretical question about the Neurodiversity Movement: "Why did it emerge in Autism Communities, though not in Mild Cognitive Impairment Communities?" Some answers are found by searching the literature for the origins of neurodiversity, then comparing the history with studies of MCI and the circumstances and experiences of persons with MCI. The article begins by examining neurodiversity, its paradigm and movement. Next, we consider MCI as a neurological condition which appears to be a suitable candidate for "neurodiversity." After pondering and deliberating, the findings are five factors which provide credible explanations for the lack of a MCI neurodiversity movement and for why a neurodiversity movement faces difficulties taking root in MCI communities. Conceptually, neurodiversity thinking need not be exclusive to autism. In fact, its effective usage in the autism community can be a helpful roadmap.*

## **KEYWORDS**

*neurodiversity, neurodiversity movement, autism, mild cognitive impairment (MCI), advocacy, social movements*

## INTRODUCTION

“Neurodiversity” is a concept which challenges ideas of the normal, describing the array of different neurological types, where the neurological variation is determined by different combinations of traits (Paletta, 2013). Some find the notion of neurodiversity to be terminologically and scientifically vague (Rebecchi, 2023), in that “neurodiversity” is not a scientific term but a political term “based on a recognition that the Autistic Self-Advocacy Movement was shaping up to be the last great identity politics movement to emerge from the modernist era” (Singer, n. d.). Thus, neurodiversity may refer to a sociopolitical movement, the social model of disability, the medical model of disability, and other meanings (Rebecchi, 2023). A related concept of neurodiversity relates to a model or paradigm.

A broad movement grew with the concept of neurodiversity. However, the “neurodiversity movement” is a contested field with different opinions, questions raised, and issues discussed (Fenton & Krahn, 2007; Guest, 2020; Jaarsma & Welin, 2012; Perry, 2012; Runswick-Cole et al., 2016; Rebecchi, 2023; Shah & Holmes, 2023). Another area of debate is the “autistic voice” that supports this movement (Woods et al., 2018, p. 975). We find strong and vocal views about particular perspectives, often found in academic settings and also expressed by authors and advocates.

Instead of defending evolving positions, the neurodiversity movement could be analyzed to see if it might benefit groups which experience disability, e.g., cognitive impairments. The movement which emerged in the 1990s through online groups of autistic persons is now linked with a civil rights quest for all diagnosed with neurological or neurodevelopmental disorders (Jaarsma & Welin, 2012; Silberman, 2015).

Following this more open and inclusive outlook to other instances of neurodiversity, “the infinite variation in neurocognitive functioning” (Walker, 2024), it seems reasonable to extend the neurodiversity paradigm to other brain conditions which have social consequences, such as Mild Cognitive Impairment (MCI), which have not normally been associated with the neurodiversity movement.

Since the origins of the neurodiversity movement are found in the autism community, their activists and advocacy (Blume, 1997; Bortha et al., 2024; den Houting, 2019; Kapp et al., 2020), it seems that it is a natural source to turn to and compare with. For a brain condition affecting cognition and life, the question can be asked, “Why has the neurodiversity movement proposed and practised by autistic scholars and activists not been adopted in MCI communities?” This article seeks answers to a curious absence of a neurodiversity movement in MCI. The article begins by examining neurodiversity, the neurodiversity paradigm and its movement. Next we consider MCI as a neurological condition, and including other conditions in neurodivergence. Finally, analyzing the neurodiversity movement’s originating circumstances, we investigate five factors which help account for the lack of a MCI neurodiversity movement. Conceptually, neurodiversity thinking need not be exclusive to autism. In fact, its effective usage in the autism community can be a helpful roadmap. Before starting, there are some comments about some concepts and the methodology.



## CONCEPTS

In this article, we follow Nick Walker's frequently cited definition of neurodiversity: "the diversity of human minds, the infinite variation in neurocognitive functioning within our species" (Walker, 2024). There are some other terms related to neurodiversity.

The "neurodiversity paradigm" concerns the spectrum of neurological variation and presumes that diversity is natural, with power relationships amidst inequalities characteristic of other forms of human diversity e.g., race (Walker, 2012). While the neurodiversity paradigm is not exclusive to autism, an autistic autism researcher sees the autism community as the one "who created the paradigm and live by its values every day, and we work inclusively and collaboratively alongside those whom our research stands to impact most – the autistic community" (den Houting, 2019; p. 272). The paradigm is thoroughly bonded to autism. Then, there is a movement based on neurodiversity.

The "neurodiversity movement," which emerged in the 1990s through online groups of autistic persons, is now linked with a civil rights quest for all diagnosed with neurological or neurodevelopmental disorders (Jaarsma and Welin, 2012). The neurodiversity movement adopts the neurodiversity paradigm and places value on human differences it believes deserve respect.

There is also the concept of "neurodivergent" which refers to "neurologically divergent from typical" and it "just means a brain that diverges" (Neurodivergent K., n.d.). Neurodivergence is "the state of being neurodivergent" (Walker, 2024). "Neurodivergence" as Walker explains can be mostly or wholly genetic and innate, for example, autism and dyslexia. Alternatively, "It can be largely or entirely produced by brain-altering experience, or some combination of the two" (Walker, 2024) such as long meditation practice and trauma.

Finally, MCI is "a syndrome defined as cognitive decline greater than that expected for an individual's age and education level but that does not interfere notably with activities of daily life" (Gauthier et al., 2006, p. 1262). The MCI concept identifies "this intermediate stage of cognitive impairment that is often, but not always, a transitional phase from cognitive changes in normal aging to those typically found in dementia" (Petersen et al., 2014, p. 214). MCI is not a synonym for mild intellectual disability. People with MCI commonly have mild problems carrying out multifaceted functional tasks which they used to undertake, e.g., shopping, meal preparation or making payments (Albert et al., 2011). MCI and those affected by it are worthy of further thought.



## METHODOLOGY

The literature is challenging to navigate safely and is accompanied by increasing hostility toward autism professionals and researchers, in favour of autistic experiences (Bolton, 2018). The autistic impulse for recognition increases and “cries for ‘nothing about us without us’ grow ever louder,” though the result is “the creation of a hurtful, quickly widening divide which is only impeding positive change” (Bolton, 2018, p. 981) Some disagree on the role of non-autistic or neurotypical individuals and parents, and about who may speak for autistic children, and the place of parent advocacy (Bumiller, 2013; Fenton & Krahn 2007; Hart, 2014; Perry 2012; Rebecchi, 2023). The views are frequently polarized.

Moreover, there is little agreement on who are accepted as authors. Woods et al. (2018) refers to neurodivergent activist academics, the autistic voice, autistic academics and non-autistic academics, and calls for a broader debate to “decide on what counts as key literature in CAS [critical autism studies], both autistic and not” (Woods et al., 2018, p. 978). Others acknowledge views claiming that “non-autistic academics do not have the right to publish in this area without including autistic authors who agree with the neurodiversity ideology” (Guest, 2020, p. 158). It seems the scholars and their scholarship are subject to intense scrutiny and debate.

While these issues are acknowledged, we seek the relevant Anglophone peer-reviewed literature, which recounted the origins of the neurodiversity movement in autism communities as well as how the concept of MCI began and developed. The databases used included Scopus, Web of Science, ProQuest, PubMed, and various internet searches. The limited results for searches on such keywords as “neurodiversity and origins” and “neurodiversity and autism” were assessed for possible significance to MCI. Those retained were writings that contained ideas which offered clues in researching why there is no neurodiversity movement evident in MCI communities. On the subject of including others in neurodivergence, there is a limited professional literature and thus we learnt from the available published works as well as the ideas of expert and lay experiences of “stories from the frontline” (Kapp, 2020). We begin by exploring neurodiversity, the neurodiversity paradigm and its movement.

## NEURODIVERSITY: A PARADIGM AND MOVEMENT

Neurodiversity is a term to describe how there is not one way for a brain to be normal, since there are many ways for the brain to be wired (Baron-Cohen, 2017). Neurodiversity is also an umbrella term to cover other neurodivergences (Raymaker, 2020; Singer, n. d.). The term originated with Judy Singer who wrote in 1998 [sic.] about the “autistic spectrum” as a call for a politics of Neurological Diversity, or ‘Neurodiversity’ (Singer, 1999). However, a recent discovery found the “neurological diversity” concept was “developed collectively by autistic and cousin’ members of the autism rights/neurodiversity movement, certainly by 1996, and likely earlier” (Botha et al., 2024, p. 1592). In any case, the “neurologically different” are a “new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability” (Singer, 1999, p. 64). These ideas lead to a “paradigm” centre on neurodiversity.

The neurodiversity paradigm is a perspective on neurodiversity as a natural and valuable form of human diversity (Walker, 2024). This paradigm invites a moral framework concentrating on

what a person can do, not pathologizing their struggles (Baron-Cohen, 2017). It has a positive outlook on diversity and yet it also raises questions.

People question the social values reflecting beliefs in society. Dyslexia is contrary to the belief that every child should be able to read, when over a century ago in an agrarian world, only the privileged were expected to be literate (Armstrong, 2010). This is applied to autism which demonstrates for example that sociability lies on a continuum between “virtual total social isolation” to the “highly sociable” and even “the overly sociable” (Armstrong, 2010). The neurodiversity paradigm based on diversity and brain recognizes and promotes the unique strengths of individuals, rather than focus on the deficit or dysfunction (Armstrong, 2012).

Before continuing, it is important to consider the issue of language and identity in relation to disability and autism.

### 1. An Identity, a Movement, and Activism

The neurodiversity paradigm influences some authors to follow *identity*-first language (e.g., “autistic people”) rather than *person*-first language (e.g., “people with autism”). Such disability-first language emphasizes identity (Kenny *et al.*, 2016). However other scholars use person-first language to avoid the negative implications (Cascio, 2015). Still others employ both person-first and disability-first language (Baker & Leonard, 2017), as this article does to acknowledge the differences of practices before proceeding further.

Identity and the neurodiversity movement found a home in the autism community. An autism-inspired neurodiversity identity engenders an “autism pride” wherein autism is a naturally occurring neuro-variation that ought to be celebrated rather than eliminated (Cascio, 2012). Their condition does not need “fixing”.

Many reject a medical model of autism and the need for treatments (Kirkham, 2017; Sarrett, 2018). At the same time, the neurodiversity movement arising from autism, while disagreeing with particular methods and goals of interventions, does support conventional medicine for treating illnesses, and therapies to foster useful skills e.g., language (Kapp, 2020).

These ideas inform a broad “neurodiversity movement” in autism communities. On social media the neurodiversity movement networks with other autistics and parents with autistic children, as well as providing a space for self-help organizations (Blume, 1997; Friend, 2014). There is a sense of community within various groups for parent support, or for overcoming social isolation, for recreation, and simply finding other similar people in the online world.

Now we turn to a different brain-related condition which is arguably an example of neurodiversity called Mild Cognitive Impairment.

### INCLUDING OTHERS IN NEURODIVERGENCE

Some see the neurodiversity movement including other conditions like Attention Deficit (Hyperactivity) Disorder [AD(H)D], dyspraxia, and dyslexia (Graby, 2015). Neurodivergent people may be those who have dyscalculia and/or other learning support needs (Pollak 2009), dementia, depression (Armstrong, 2010; Jackson, 2017), psychopathy (Anton, 2013; Ramirez, 2016), and those identifying as Mad (McWade *et al.*, 2015). But the list need not end there.

schizophrenia (Armstrong, 2010; Baker, 2011; Graby, 2015; Kapp, 2020; Tew, 2017), mood disorders and anxiety disorders (Armstrong, 2010); additionally, those with late-stage dementia (Russell, 2020), or intellectual disability (Armstrong, 2010; Baker, 2011; Russell, 2020). Many examples of neurodivergence are possible.

Naturally, there will be varying opinions, disagreement, and vigorous debate. For this reason, it is important to continue thinking about the neurodiversity movement. This has a benefit: “How successful the movement is will, to some extent, depend on how viable its underlying concepts and theoretical basis are” (Chapman, 2020, p. 218). One might think of a “big tent,” e.g., a “solidarity network of movements fighting for radical acceptance of all types of human diversity” (Graby, 2015, p. 241), and “the opportunity for other people to identify and organize within the movement” (Kapp, 2020, p. 4).

Autistic scholar Dora Raymaker sees neurodiversity as a celebration of varieties of minds, an acknowledgment of “the necessity of diversity in order for society to survive, thrive, and innovate”; what covered her was a “huge, multi-coloured neurodiversity umbrella: we the autistic, the mad, the weirdly wired, the queer, the crippled, and the labelled with neurodivergent diagnoses like flowers that glorify our beautiful bodies and minds” (2020, p. 142).

Another view comes from Monique Craine, an activist diagnosed with dyslexia, then dyspraxia/Developmental Coordination Disorder (DCD), and later diagnosed on the autism spectrum, speaks to “the Neurodivergent community instead of the segregated individual dyslexia, DCD, ADHD, Autism, etc., online groups. It is why I work toward unifying all the ND minority groups under one more natural banner” (2020, p. 259).

There are ideas about seeing neurodiversity in mental illness conditions. Some scholars have concerns that mental illness is appearing as a socially constructed category including “neurodivergence pathologized” and “distress experienced as a result of psycho-emotional disablism or other forms of oppression” (Graby, 2015, p. 237). Graby explains that “proponents of neurodiversity” would likely ask questions about some divergent neurotypes that are distressing, such as sensory intolerances and/or auditory processing difficulties. He acknowledges these could be “inherently” distressing due to biochemical factors, but it could be “more a matter of social and environmental surroundings not being suited to the individual” and these are “the result of unfair and oppressive social conditions” (2015, p. 237).

Neurodivergent conditions could be psychiatric disability or mental illness (Neumeier and Brown 2020). Arguments for including “neurodivergent conditions like bipolar disorder, schizophrenia and Parkinson’s disease could also be made” (Mackenzie & Watts, 2011c, p. 48; see also Antonetta, 2005; Baker 2011; Graby 2015; Russell, 2020). These perspectives are noteworthy in thinking about neurodiversity.

Continuing with our examination of diverse neurological conditions, some propose neurodivergence in anorexia, body integrity identity disorder (BIID), and callous unemotional conduct disorder (CUCD). These three groups may be framed as “atypical neurological information processing – the definition of neurodiversity suggested by DANDA [Developmental Adult Neuro-Diversity Association] – yet none are included within the conditions DANDA lists as neurodiverse” (Mackenzie & Watts, 2011b, p. 32).

Another scholar Robert Chapman saw his post-traumatic stress as a genuine mental disorder and his autism as a valuable manifestation of human genetic diversity. Now, however, he thinks of those labelled with disordered personalities as it was for many autistic people, “why should it matter if any given set of traits is ‘natural’ or not anyway? I rather think the focus on whether things are natural or not often detracts from more important goals” (2020, p. 219). Chapman thinks neurodiversity is an “epistemically useful concept” and “from this perspective, a core function of the concept regards how it helps us imagine the world differently to how it currently is” (p. 219).

Coming back to MCI, others ponder the neurodiversity movement including neurodegenerative conditions (Russell, 2020). People with dementia experience meaningful interactions differently from neurotypicals. A neurodiversity paradigm considers, “those with dementia as part of a society that embraces other diversities as well – ethnic, gender, culture. There isn’t a ‘normal’ or ‘healthy’ type of brain or mind, or one ‘right’ style of neurocognitive function” (Paul, 2015). They are called “neurodivergent patients” living in a “neurodiverse household” using neuro-cognitively diverse strategies to assist them in an environment not conducive to their “particular neurodiverse abilities” (Paul, 2015).

Furthermore on the affinities between dementia and autism (Hodges, 2023; International Summit Autism/Dementia Work Group 2024; Nadeem *et al.* 2021; Rhodus *et al.*, 2020; Sakuta *et al.*, 2021), some researchers have analyzed “wandering”: movement through space without intention or destination (Solomon & Lawlor, 2018). The autistic child who wanders prompts parents “to comprehend their child’s subjectivity by imaginatively tracing his or her movement through space” (p. 209).

Wandering is a concept sometimes used in autism research (Adams & Kaur, 2024; McLaughlin *et al.*, 2020; Plummer *et al.*, 2021). Wandering is often also called “elopement” when an individual vacates a safe area or departs from a caregiver (Rice *et al.*, 2016). Families of children with autism have described how these children are at risk of harm by eloping or wandering (Anderson *et al.*, 2012).

Solomon & Lawlor’s study challenges notions of “wandering” as meaningless or lacking intention usually held in biomedical approaches to autism and dementia, which cast people with these conditions as “erratic ... when a person’s movement through space is deemed aberrant, he or she may be construed as irrational, a danger to self because of a lack of self-awareness, and a danger to others because of a lack of empathy” (Solomon & Lawlor, 2018, p. 211). Here, there are resemblances in behaviours and if autism is neurodivergent, then dementia could be likewise understood.

Finally, consider ideas about free will and agency which relate to notions of competence, medical decision making, and the emotions. Neurodiversity, as neurologically based variations in information processing, also affects measures of competence, especially in atypical emotionality connected with atypical neurological makeup (Mackenzie and Watts, 2011b).

Atypical emotional functioning is often linked to neurodegeneration, e.g., behavioural variant fronto-temporal dementia (bvFTD). Assessments of the ability of these neurodegenerative groups to engage in neurotypical decision making are frequently influenced by their emotional

behaviour (Mackenzie & Watts, 2011b), e.g., those with bvFTD will lose their ability to feel empathy.

As to “when atypical emotionality should be accepted as neurodiversity rather than pathology and how it should impact upon competence assessment are clinical and normative questions without clear answers” (Mackenzie & Watts, 2011b, p. 30). While the origins of these “neuro” conditions are not explored, the use of a neurodiversity perspective is evident and represents another reason to think more neurodivergently about dementia.

In all, there is an assortment of medical and mental health and perspectives in relation to neurodiversity. They offer different voices which can contribute to discussions about terms and interpretations.

Having examined neurodiversity, the neurodiversity paradigm and its movement, as well as considering MCI as a neurological condition, and including other conditions in neurodivergence, we turn to our central focus of MCI.

### **MILD COGNITIVE IMPAIRMENT**

“Mild Cognitive Impairment” was used in 1988 to describe a clinical scale for memory “deficits” (Reisberg *et al.*, 1988). In 1999 a study characterized quantitatively the changes in patients diagnosed with MCI using criteria used in multicenter treatment trials (Petersen *et al.*, 1999). The results demonstrated how subjects were at greater risk of developing Alzheimer’s disease (AD). The research led by Ronald Petersen from the Mayo Clinic in Minnesota, delineated diagnostic criteria which have been further investigated, validated and critiqued (Petersen *et al.*, 2009). MCI nowadays is a developing yet debated category.

There are several systems perspectives on MCI. More recently, cognitive functioning is normally grouped into one of five domains: (1) learning and memory, (2) language, (3) visuospatial, (4) executive, and (5) psychomotor; these domains have general associations with their cerebral localization (Knopman & Petersen, 2014). For MCI diagnosis, one of these domains must be impaired, whereas a dementia diagnosis needs more than one domain impaired. If memory loss is the predominant symptom, the term “amnesic MCI” (aMCI) is often used, where the patient’s memory impairment does not accord with what is expected for their age and do not meet the criteria for AD (Grundman *et al.*, 2004). The others are “non-amnesic” (naMCI).

Like autism, MCI is an example of neurodivergence which affects the lives of those with MCI, though differently to autism. Some themes in research with MCI patients and families are: uncertainty, skill loss, change in roles, embarrassment and shame, and burden (Lori *et al.*, 2006). For instance, on skill loss, “I don’t bake any more... I just kind of lost interest in it. (MCI patient)” (Lori *et al.*, 2006, p. 157).

Such data from patients and families inform the delineation between MCI and AD, which was based on whether the cognitive impairment interferes with activities of daily living (Morris, 2012). But revised criteria for MCI now alter this distinction by allowing mild difficulties in functional activities to be part of the MCI spectrum.

Consequently, a majority of individuals currently diagnosed with milder stages of AD dementia now could be reclassified as having MCI. In fact, MCI as a term rose in popularity, perhaps due

to how it permitted clinicians to avoid applying the stigmatizing label of Alzheimer's or dementia (Whitehouse, 2016). MCI has been established as a useful diagnosis.

Having considered the subjects of identity, autism, and MCI, it is timely to think about enlarging the range of what may be considered as which neurological conditions could more explicitly be understood as neurodivergent.

### **WHY IS THERE NO NEURODIVERSITY MOVEMENT IN MCI?**

Autism and MCI have particular cognitive and behavioural indicators. These are due to differences in the brain which could be interpreted as being diverse from the neurotypical population. Both MCI and autism have diagnostic criteria to identify persons with their indicators, a "clinical identity" alongside their families and supporters.

There are also affinities between autism, MCI and neurodivergence when we consider adulthood, stigma, and excluded groups. Although MCI occurs in adulthood and autism is a lifelong, yet the diagnosis rates of autism among adults has increased (Lowinger and Pearlman-Avni, 2019). With MCI, the experience of receiving a diagnosis includes the perceptions of a threat, emotional reactions, and a threat of stigma of cognitive impairment (Morris *et al.*, 2020).

Some ways to cope with the threat in MCI are minimization through language, sharing information and withholding it, and utilizing social support. "Dementia and cognitive impairment have a long-standing historical association with the lay concept of 'madness' and in some instances criminality" (Morris *et al.*, 2020, p. 128). This is comparable with autism. With adult autism diagnoses, they imply a "dysfunctioning," an "abnormality," and the choice between finding recognition in the diagnosis but coping with the stigma. "Should you tell people or not?" (Hens & Langenberg, 2018, p. 117). There can also be a stigma associated with psychiatric disorders, and a stigma towards autistic adults (Epstein, 2019; Vortman-Shoham & Kenny, 2019).

There are also comparable ways to cope as Morris *et al.* (2020) found in MCI. Through language, Botha *et al.* (2020) noted unfavourable comparisons have been made between autistic individuals and robots, animals, or sub-humanness. Participants seem to use language as a reclamation of stigmatized labels, using identity-first language to destigmatize them. Then regarding sharing and withholding information, this can be related to diagnosis of autism in adulthood and the use of "camouflaging" of autistic characteristics by using methods to conceal social difficulties, appearing socially competent and "passing as though non-autistic in social situations" (Perry *et al.*, 2022, p. 800). Finally, using social supports also features in autism. Autistic adults generally report noticing, expecting and experiencing public stigma and stigma-related supports are valuable, such as strategies which encourage "sharing the right information with the right person at the right time" (Han *et al.*, 2023, p. 1685). Sometimes, as for MCI, individuals will consider strategic disclosure to ensure they have support, legal protection from discrimination, and avoid the stigma of public disclosure (Rosqvist *et al.*, 2020). These are common experiences.

Another autism concern shared with MCI is exclusion. There is concern that variations and complexities of autistic people in areas of race, colour, gender. Other marginalised persons are not fully represented in autism studies (Botha & Cage, 2022; Cascio *et al.*, 2021; Mallipeddi &

VanDaalen, 2022). Autistic individuals are frequently excluded from research because of being verbally limited or non-verbal. “This exclusion demonstrates how the academy privileges certain kinds of knowledge, accessed by particular kinds of research methods” (Bertilsson *et al.*, 2019, p. 1089). Researchers sometimes have kept away from first-person testimony, instead “preferring to privilege reports from parents, teachers or other informants, or laboratory-based observation over considering the perspectives of the person themselves” (Pellicano & den Houting, 2022, p. 385).

Similarly, the experiences of those receiving MCI care have been neglected when research excludes individuals with cognitive difficulty because of the assumption that participants’ responses might not be valid (Schneider & B. Kahana 2019). Consequently, older MCI patients may be regarded like racial minorities excluded from studies as underserved populations. Correspondingly, those with dyslexia, Tourettes, or AD (H)D, may not easily appear in academic neurodiversity discussions due to stigmatization (Rosqvist *et al.*, 2020). Hence, “it is essential for neurodiversity studies to consider all neurodivergent differences and not to exclude types of neurodivergence that are seen as less culturally palatable. Rather, we want to argue that it is the responsibility of society to find a way to accommodate all variations, and for scholars to explore them rather than dismiss them” (Rosqvist *et al.*, 2020, p. 227).

In short, MCI and some forms of autism are not diseases which necessitate urgent intervention. Both situations need personal, social and family adjustments and can benefit from planning and management. Nevertheless, for autistic people there is a neurodiversity movement; for MCI, there is not. In light of what is common to both, one may wonder about the apparent absence of explicit neurodiversity thinking and action within MCI.

Some clues to the puzzle appear to be found in differences. For instance, the vocal arguments of the autism neurodiversity movement against treatment have not been heard in experiences with MCI. Treatment or interventions can be viewed as therapeutic responses using various strategies or techniques not intended to prevent, cure or eradicate autism (Baron-Cohen, 2017)., Rather, they address the symptoms associated with autism and strengthen functioning and outcomes (Masi *et al.*, 2017; Pardini *et al.*, 2012; Wilson *et al.*, 2018).

Thus, the differences of autism and MCI are early indications of the prospects of finding potential answers to our investigations. From our analyses, we propose five factors which help account for the lack of a MCI neurodiversity movement.

## 1. Fundamental Perceptions

There is an unlike perception of MCI compared with autism. Individuals have differences in functionalities which affect their capabilities of interacting successfully with the infrastructures of society. The sociopolitical infrastructures include legal, ethical, financial, occupational, health, and educational structures. Baker (2011) identifies four possible outcomes: difference, impairment, disability, or “handicap”. *Differences* involve no alteration in individual potential or social standing. *Impairment* occurs where the difference is noticed by society and deemed potentially inconvenient for individuals or society, to the extent that it may possibly be assisted or corrected by medicine, treatment, or device. For example, near- and farsightedness are considered impairments given the importance attributed to “perfect” or “corrected” vision. The

term “impairment” need not inevitably imply reduced social status or inability to be included in society except via minor inconvenience.

*Disability* happens when there is an impairment of major life functions including activities essential to full membership of society (Baker, 2011). *Handicap* [sic.] are those interactions between human differences and society that unavoidably generate lowered social status, e.g., the challenging infrastructures on most public transport systems are generally not thought to be desirable in society.

The neurodiversity paradigm in autism focuses on diversity, that is, legitimate *differences* arising biologically from brain structures and functions. Whereas MCI is not explicitly framed within a paradigm of differences. How MCI is usually perceived is important. For persons with autism and their relatives: autism is perceived as significant since it determines any stigma linked with the diagnosis, and, moreover, perceptions shape the paradigms in the minds of clinicians and researchers involved in assessments, investigations and interventions (Bölte & Richman, 2019).

Then there is increased public policy attention on neurological disabilities: the brain is now better understood; and children are more often diagnosed with neurological differences than previously (Baker, 2011). Thus, policy agendas focused on “neurological differences may become conflated with modern parenting goals. Also, public representations of individuals with neurological differences most often focus on children” (p. 16).

Another consideration is the time of onset. Clinical diagnosis of autism in very young children at 20 months has proved to be highly sensitive and stable using an autism spectrum approach (Cox *et al.*, 1999). Autism is a lifetime neurodevelopmental disorder, and people with autism experience a lower quality of life than those without autism, with no overall substantive evidence of quality of life improving or deteriorating over a lifespan (van Heijst & Geurts, 2015).

Conversely, MCI is routinely associated with the elderly who are at risk for developing AD (Celsis, 2000), which affects people differently to autism. The elderly may disclose cognitive problems to their physicians, but they may be unwilling to share the extent of their limitations with others and may not seek or receive suitable help in a well-timed manner (Roberto *et al.*, 2011). This could be due to ageing and fears.

There are variations in how people envision very old age and their ideal life expectancy which relates to fears about living conditions in very old age. Researchers found persons with a strong fear of death wished to live the longest lives, but persons fearing aging-related diseases or loneliness in old age but unafraid of death wished to live shorter lives (Rupprecht *et al.*, 2022).

In brief, public policy, discussions, and the age of manifestation tend to steer MCI into a position of impairment which is viewed as undesirable and in need of possible treatment. MCI does not yet have an articulated movement of neurodiversity.

## 2. Unfavourable Association with Dementia

The conceptual resources are ready for MCI to be a participant in *neuro-diversity*. However, there is a larger context of *neuro-degeneration*. This is another factor which is different in that Autism is not a disease which causes a deterioration in mental status over time (Baker, 2006). Whereas MCI is associated with dementia. The two decades following retirement age (middle 60s) can

be satisfying, nevertheless those decades are “marred” by fear of developing AD, described as “horrible, insidious, currently incurable and extremely costly in terms of palliative care” (Reid *et al.*, 2017, p. 163).

A survey of the United States, France, Germany, Spain and Poland found that in four of the five countries, AD was the second-biggest health fear after cancer, and about a quarter of adults in four of the five countries say they most fear getting Alzheimer’s disease (Blendon *et al.*, 2011). Even young adults are concerned, where approximately one in seven 18- to 34-year-olds reporting Alzheimer as the disease they are most afraid of.

As patients said, “It’s feared just like cancer is. It’s a death sentence... A loss of the capacity to be oneself. And it’s frightening. It’s the worst of all insults” (Beard & Neary, 2013, p. 140). When asked why, the answer was, “Because I suppose above all things we prize ourselves, who we are, who we have come to be, what we have been and what we can be and if we lose all that we’ve lost everything... Because they would rather be crazy than have Alzheimer’s... It’s a death sentence. It’s over.” (p. 140)

Given that the pathobiological process of AD starts in the brain decades before the onset of explicit symptoms, it is logical that strategies to “combat dementia” target preclinical detection (Mitchell & Black 2016). Approximately 15 percent to 20 percent of people aged 65 or older have MCI and people with MCI, particularly MCI involving memory problems, are more likely to develop Alzheimer’s or other dementias than people without MCI (Alzheimer’s Association, 2018).

In 2020, the first group from the baby-boomer generation has reached 65 years of age or exceeded it; psychologists expect baby boomers to have anxiety about dementia and will look for diagnosis and treatment in larger numbers, particularly MCI (Karel *et al.*, 2012). The international predictions for dementia and AD therefore make it harder for those with MCI to think about neurodiversity and to champion MCI outside of a medical model. People diagnosed MCI can reflect negative perception of AD as the slow death of the mind and the biomedical concerns for cause and cure instead of *living with* Alzheimer’s (Beard & Neary, 2013). Contemporary media representations and public awareness of Alzheimer are almost entirely pejorative despite the extensive literature showing meaningful lives of such individuals. There is a loss-of-self rhetoric which includes thoughts about the “loss of function as a human being” and “a loss of capacity to be one’s self” (Mitchell and Black, 2016, pp. 15-16).

Interestingly, advocacy organizations have been slow to help contest this discourse (Beard & Neary, 2013). With more diagnosed with MCI earlier in the AD disease process, personal accounts of the condition have yet to be brought forward (Beard, 2004). A reason given is that Alzheimer’s Association with its biomedical research character favours particular aims such as a cure and prevents others like quality of life and an interest in how people live with the disease. The US Alzheimer’s Association, along with Alzheimer Europe has this concentration on professional and “expert” voices (Schicktanz *et al.*, 2018). These are organizations focused on AD rather than MCI.

Nonetheless research shows individuals diagnosed with MCI can sometimes not progress to dementia, or they can revert to normal cognition (Overton *et al.*, 2023) sometimes with high reversion rates of 58% (Overton *et al.*, 2020). Such findings are lesser-known and have yet been exploited to inspire a neurodiversity movement.

All up, it seems that a contributing factor for there being no neurodiversity movement for MCI is its status as a neurodegenerative phase that frequently, though not inescapably, leads towards AD. MCI is also understood within a medical model of cognitive ageing and prevention of dementia, which can also be framed as preventing cognitive impairment and disability in the at-risk elderly population (Ngandu *et al.*, 2015).

### 3. Difficulties in forging an identity of diversity

The dual challenges of fundamental perceptions and the fear of AD dissuade an identity for MCI matching the autism neurodiversity movement. The third possible factor is patient experiences and thoughts, which would influence their sense of identity which differs from their previous neurotypical one. Examples commonly reported being loss of skills in areas like handling finances, and lessened involvement in normal activities such as hobbies and problems with planning and spatial orientation (Dean & Wilcock, 2012). MCI is demanding to grasp for those diagnosed, as it involves a complex relationship between “normal” aging, neurocognitive disorders, and MCI (Gomersall *et al.*, 2017).

As a clinical label, MCI is useful but few participants in a British study of people with MCI and their families identified with the label; they found it had limited explanatory ability to clarify their problems, though there was an emphasis on trying to live, “normally.” (Gomersall *et al.*, 2017). It appears probable that people with MCI are likely to continue living with uncertainty. Naming a condition can alter a set of signs and symptoms into a “known” condition, potentially providing choices for clinical management and alleviation of suffering. Nonetheless in the UK, no specific treatments are currently recommended for the medical management of MCI. This was a source of frustration to several participants in the British study. Many desired medical management to apprehend further decline.

Importantly, the above discussion of MCI impairments does not imply that some experiences of autism are less impairing. Moreover, intellectual disability can intersect with autism and can even be commonly a co-morbid disorder with “ASD” (Blacher & Kasari, 2016). There can be impaired functioning in the areas of communication, social skills, and behavioural flexibility in diagnoses of autism plus differences in cognitive processing of information (Cashin & Barker, 2009).

In short, persons with MCI do not identify willingly with their condition of impairment like many autists in the neurodiversity movement do with theirs, especially those spousing neurodiversity as a difference. Hence it seems improbable that there could be is a sense of a neurodiversity vision about MCI or pride in having MCI. It looks like there is little impetus for a patient-led neurodiversity movement with MCI.

### 4. Less Internet-Enabled Activists and Activism

The fourth possible factor is social media which can be used to disseminate counternarratives, e.g., the cyberactivism of autistic self-advocates enabled bonding in ways that aid the development of an empowered community (Parsloe & Holton, 2018). Using the former Twitter now X, cyberactivists facilitated disability activists to find new ways to reconfigure discussions about autism and other disabilities, e.g., a digital trend in autism communities from peer support to civil rights and advocacy is noted for the discussion’s “heated rhetoric” (Bolton, 2018).

This scope of internet activist involvement is not a common feature of MCI. Researchers analyzed Mild Acquired Cognitive Impairment (MACI), a non-progressive mild cognitive impairment after an acquired brain injury (Eghdam *et al.*, 2018). They investigated how persons with potential MACI, persons with perceived brain fatigue after brain injury, communicate through Facebook. The most recurrent subjects in their communication were related to informational support and banter in posts, and socialization in comments. The most used communication feature of Facebook was like in the “thumbs-up” graphic. Communication behaviours of people with potential MACI were found to be comparable to the healthy population.

Age may be a factor. Other older adults who use social media such as Facebook, Facetime, and Whatsapp found barriers not reported among autists, e.g., “To be honest, I do not fully understand social media. My children installed it at the time, otherwise I would have no idea” (Aarts, 2018, p. 554). The most important device for fulfilling social needs was not a smartphone but the landline telephone (ten Bruggencate *et al.*, 2019). This contrasts with the more influential impact of media use by autism neurodiversity advocates.

Here we can apply a model of online communications from the perspective of the public sphere, comprising four generalized functions (Rauchfleisch & Kovic, 2016). First, *Identity Building*, facilitated by access to communications. A sense of collective identity within a group of people is the primary function of the public sphere. However, if only a minor segment of the people has access to the Internet and communicates online, then a collective identity cannot really form. This is what the MCI “community” as it seemed lacking.

The second function is *Agenda-setting*, which relies on a critical mass of people. Once the building of an identity establishes a degree of permanence in the collective identity, it becomes likelier that the “political elites” will be receptive to public communication and agenda-setting can occur. Online communication can merge into communication flows which stimulate reactions from political elites. This is evident for autism in general, though not so for MCI because the first step of collective identity has not yet been reached.

The third function, *Control and criticism*, happens after the first and second functions reach some permanence (Rauchfleisch & Kovic, 2016). The agenda setting develops into an exchange described as control and criticism. Political elites are receptive to responses mounting from the public through an agenda setting; then political accountability alters this process when the public then reacts to the actions of the political elites. Consequently, there are further stimuli; the political elites once more are receptive and hence a policy cycle emerges. Online communications can be part of the policy cycle through easy and rapid observations and feedback from the public.

Lastly, the function of *Deliberation* occurs when the above functions attain some permanence. The public sphere is such that deliberation or rational disputes over claims of validity can enter the realm of the possible. The Internet is a space for communications which is an ideal forum for discussions where everyone questions claims and submit new claims (Roberto, 2011).

MCI has not achieved the higher functions as it appears only at the first function of identity. Undoubtedly, the technological infrastructure and potential networking power are there. MCI

identity seems to need further development before its deployment across cyberspace. This also requires skills to use internet-enabled technologies, which likely depend on age.

## 5. Other Advocates and Activists

A fifth factor to consider is how the neurodiversity movement has benefited from the work of other advocates. Autism scientists and researchers are engaging with the public and autists, though there can be difficulties between essential political differences within the autistic community and impairments particular to autism (Hollin & Pearce, 2019). Carers may advocate for resources for the autistic person in a continuing struggle to receive support from educational, health and social services (Reading, 2018). Advocacy by neurotypical allies to promote neurodivergent people is appreciated by many autistic self-advocates, yet these self-advocates also highlight how there is no substitute for self-advocacy among neurotypicals (Tumlin, 2019). Autistic self-advocates believe that they ought to be in the lead, either as equal partners with neurotypicals, or independently.

For MCI, older adults may not engage in self-advocacy and prefer physicians' advocacy, with no "patient empowerment" or "empowerment paradigm" (B. Kahana *et al.*, 2018, p. 1162, p. 1167; Schneider & E. Kahana, 2019). Activism and advocacy come from carers and partners seeking better services and information. Care partners can have negative experiences with medical professionals, e.g., a lack of discussion about the nature or prognosis of MCI (Pasymowski *et al.*, 2013). Overall, they are not constructing a liberating neurodiversity movement.

There is also more interest in treatment than activism. Varieties of cognitive rehabilitation have been trialled with people with MCI or early dementia, and the clients and their supporters e.g., adult children, were generally interested in acceptance, cognitive improvement and client goal achievements in everyday living (Regan & Wells 2017; Regan *et al.*, 2019). The cognitive interventions included learning new strategies, e.g., remembering to take a walker (mobility aid). The supporters and counsellors were attentive to the clients' skills, mental state, and "coming to terms" with their diagnoses. One counsellor saw the role of the carer as significant, "in some of the situations the supporter has been only kind of tangentially supportive. But he [the husband] was very actively involved, in printing things off the computer to help prepare their reminder charts and so on" (Regan *et al.*, 2019, p. 4).

This might imply that if the level of support services desired were adequate, there may be more interested in socio-political activism to achieve outcomes like increased funding for evaluation of treatment research and quality of care, boost patient and carer engagement with clinical trials, and services for MCI caregivers, families, and healthcare professionals (Tochel *et al.*, 2019.).

Looking to possible professional MCI activists, these are not conducive to fostering a neurodiversity paradigm. An article in a medical journal on MCI listed web resources in its supplemental online material, where the Alzheimer's Association was highlighted as a national advocacy organization supporting research and care related to AD and other dementias (Langa & Levine, 2014). MCI is generally viewed as antecedent to dementia, and health advocacy is in dementia-related fields, and not solely for MCI (Bishop *et al.*, 2015).

Other relevant organizations are regulatory institutions e.g., the US Food and Drug Administration (FDA), and pharmaceutical companies who funded a major proportion of MCI research, within the umbrella of diagnostic categories for early diagnosis of AD, its prevention



or delay, and therapeutic developments for MCI (Moreira *et al.*, 2009.). These groups are targeting treatments; not a neurodiversity paradigm for MCI.

Some guidelines suggest that MCI is undergoing a medicalization process, which reflects biomedical constructions that dominate the framing of forgetfulness over the social dimensions of MCI diagnoses (Beard & Neary, 2013). Thus, MCI is situated within a medical model which occupies stakeholders. MCI does not appear to follow the autism-based neurodiversity movement which protests any “cure” for autism. It is difficult to find advocates who espouse alternate concepts of MCI among the public health, aged care, and social services sectors.

## DISCUSSION

Some factors contributing to no MCI neurodiversity movement include: the perception of MCI as an impairment to be treated, rather than a neurological difference to be appreciated; a link with AD and dementia, with a narrative of neurodegeneration; difficulties in forming a suitable identity featuring a neurodiversity paradigm; marginal activism via electronic communications which a more robust MCI identity could exploit; and other potential advocates and activists are fewer compared to the neurodiversity movement in autism.

Comparing these factors, the first two are related. The perceptions of MCI are influenced by its close associations with AD and dementia generally. The other three factors are also linked. The difficulties in forming identity may lead to a lack of noticeable digital discussions about neurodiversity and MCI. If that is so, then there will likely be less activists advocating for a MCI neurodiversity movement. Naturally, the perceptions and AD factors are somewhat related to the factors of no real MCI movement identity to rally around, a lack of an active presence in cyberspace, and fewer advocates keen to promote a MCI movement.

These findings are new, and the early results are open to discussion and debate from the standpoints of multiple disciplines. One limitation is the preliminary nature of the research. There may be other factors which have not been considered. Another limitation is the diverse opinions about neurodiversity-related terminology, knowledge and history held by scholars and activists. The variety of views indicates the importance of neurodiversity and neurodivergence discussions, yet it was a challenge to navigate, and misunderstandings are possible. It is time to turn to the future.

## CONCLUSION

Conceptually, neurodiversity and its paradigm as theoretical and practical templates are available to be extended to other neurological contexts. Though it has not yet inspired MCI, it might be of future interest to other neurodiverse circumstances. This raises the question of whether neurodiversity as a concept born, nurtured and now active within the autism community, can be applied beyond autism. The extendibility seems to depend on the factors discussed.

Neurodiversity is a current issue as many companies are working to make their human resources “more neurodiverse” (Ovaska-Few, 2018; Austin & Pisano, 2017). While those with MCI may not have equivalent skills, e.g., a certain cognitive style, it is worth considering the retention of people with MCI in the workplace, as it would conserve the potentially valuable



contribution to society (McCulloch *et al.*, 2016). Involvement in meaningful occupation offers notable physical and mental health benefits to people with MCI whereas unemployed people are more likely to have chronic physical and mental health conditions (Vancampfort *et al.*, 2019).

Even if potential new applications of neurodiversity are not able yet to emulate the autism phenomenon, still the neurodiversity paradigm represents another vision. Neurodiversity can offer inspiration to reconceptualize MCI away from AD and dampen negativity with its associations with dementia.

Adding a neurodiversity perspective may assist in the important work of understanding and improving clinical discussions about MCI. Those who receive a formal diagnosis of MCI often do not know about MCI or are gradually understanding the prospects of hastening cognitive decline (Collier *et al.*, 2017). Moreover, what appeared to weigh most on the minds of those with MCI is the negative public images of older persons, rather than managing MCI. Introducing a neurodiversity paradigm may help encourage dialogue on such anxieties and provide new categories to frame MCI experiences apart from AD and unfavourable societal impressions of elderly persons and ageing.

Further, it counters the medicalization of disability and difference, by focusing on social factors that disable, like stigmatization and a deficiency in accommodations (Garden, 2010), while being critically attentive to social and political factors surrounding impairment and illness. These are other contexts for living with MCI, while not extinguishing hopes for prevention, better treatments and breakthroughs.

Conceivably, the real driver of change is waiting. The large cohort of children diagnosed with autism in the past 2 decades or more is approaching adulthood (Nicolaidis *et al.*, 2014). Research discussions have turned to conceptualizing the nature of aging when referring to autism, such as diagnostic measures, cognitive factors, and quality of life in older age (Roestorf *et al.*, 2019). This will be the generation of the neurodiversity movement powering that activist environment. Perhaps it will be these older neurodiversity pioneers who will be the ones to advance a MCI neurodiversity movement in the future.

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