

# Chapter 6

## ‘Connected to the Soul’: Autoethnography, Neurodiversity and Literacies in Times of Ongoing Change



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**Abstract** The COVID-19 pandemic has seen ongoing and disruptive change on a global scale. As well as being experienced collectively, this period of uncertainty has been felt intensely and personally by individuals across the world. In this chapter, I use an autoethnographic approach to provide a personal, reflective take on recent events. Here, I emphasise how individual lives are *always* subject to and unsettled by change and disruption, both *regardless of* and *inclusive of* global contexts, in order to make a case for an approach to literacy research that takes direct account of the personal.

During the first period of ‘lockdown’ in the UK, I was diagnosed as autistic. Here, I reflect on this experience in the context of wider disruption, using a literacy lens to examine the texts I encountered, and created, during this period. Considering these texts—including formal diagnostic papers, a comic, mapping and song—using autoethnography, I reflect on the process and experience of being diagnosed autistic during a time of global change. I explore the multiple meanings made around these texts and the value they brought to my own ‘precarious’ experience of the world.

This chapter both exemplifies and argues for the use of autoethnography, and other storytelling methods, as valid and necessary aspects of literacy research. I also suggest that there are benefits to encouraging stories that engage with meaning-making through the use of multiple modes. Finally, I show how literacy research could be enriched by drawing on ideas from the neurodiversity (Singer, 1999) paradigm, which deal with interrelated issues of power, value and the resistance of deficit or normative models of understanding difference.

**Keywords** Neurodiversity · Literacies · Affect · Autism · Autoethnography

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## 6.1 Introduction

This chapter offers a personal take on this book's concerns around precarity, providing an 'opening' that encourages the expansion of literacy studies through methodology and topic. Drawing on my own experiences, I exemplify and argue for the use of creative personal storytelling approaches as necessary methods in literacy research. At the outset of the COVID-19 pandemic, during the first period of lockdown in the UK, I was diagnosed autistic by the local authority's Adult Autism and Neurodevelopmental Service. Here, I recount this experience, exploring how I made sense of this emerging identity in relation to the texts I encountered, and created, during a time of personal and global precarity. I discuss these texts and reflect on their impact using three autoethnographic episodes. I combine perspectives from New Literacy Studies (NLS) (Street, 2012) and the neurodiversity (Singer, 1999) paradigm to demonstrate how both share concerns around power, value and the resistance of deficit or normative models of understanding difference. In spite of these synergies, there has been little connection made between these areas. I argue for the necessity of further work that unites these perspectives, particularly at a time in history where, politically and culturally, there is growing need to push back against populist discourses around identity and normatively framed conceptions of value.

## 6.2 Neurodiversity

In recent years, the neurodiversity movement (Kapp, 2020) has advocated for the rights, respect and inclusion of those diverging from a socially constructed 'neurotypical' (NT) human default. The term 'neurodiversity' was first introduced by Singer (1999) to describe the naturally occurring variation between human minds, particularly in relation to autism. As a 'key force in promoting social change for autistic people' (Kapp, 2020, p. 3), those aligned with the neurodiversity paradigm argue for a view of autism and other types of neurodivergence, in 'social terms of human rights' rather than 'as a medical collection of deficits and symptoms to cure' (Kapp, 2020, p. 18). The term 'neurodivergent' (ND) is also used in relation to terms such as dyslexia, ADHD, Tourette syndrome, learning disability, etc., as a means to include anyone who does not adhere to the neurotypical default. As such, neurodivergent individuals are positioned as experiencing ways of thinking, feeling, doing and being that, in contrast with deficit, medically mediated models of understanding human worth, add value to society in ways that move beyond neurotypical conceptions of the world. Nevertheless, neurodivergent people are still subject to social power inequalities (Tisoncik, 2020), what Deleuze and Guattari (1987) might call 'minoritarian' oppression in a homogenous 'majoritarian' system.

### 6.3 Autism

Several characteristics are shared by autistic people. Williams (2020) suggests that being autistic involves a 'sense of being "other"' (p. 39). This feeling often results from social misalignments that arise due to communication differences between ND and NT individuals. Challenge around verbal and/or nonverbal communication is a feature of autism diagnosis (American Psychiatric Association, 2013, p. 50). Differences in sensory processing are key aspects of autism (Belek, 2019, p. 30). Sinclair (2013) writes that 'autism is a way of being. It is pervasive; it colours every experience, every sensation, perception, thought, emotion, and encounter' (n.p.). Autistic individuals experience varying degrees of hyper- or hyposensitivity to different sensory stimuli. Autistic people also generally rely strongly on routine and face challenge in managing uncertainty (American Psychiatric Association, 2013, p. 50). I understand autism as an 'assemblage' (Deleuze & Guattari, 1987, p. 4) consisting inevitably of the more pathologised medical definitions but also being constructed from more generous sociocultural accounts of autistic experience. Referring to autism as an 'assemblage' helps to resituate the language around autism in a space beyond the medical model, expanding our understanding of autism as 'both a construct and objective part of the world' (Chapman, 2020, p. 42) whilst also acknowledging the complexity of autism as an identity rather than a deficit or a disorder (Fletcher-Watson & Happe, 2019). This is not to deny the challenges faced by autistic people but to shift understanding of those challenges as stemming from societal barriers rather than internal failure. Autism is a 'heterogeneous' experience (Fletcher-Watson & Happe, 2019, p. 159), just as being NT is a heterogeneous experience. Nevertheless, it tends to be more medically mediated conceptions of autism, and other neurodivergent ways of being, that permeate the popular consciousness, often via simplified portrayals in popular culture. Whilst autism is said to be a 'spectrum' with a wide range of variation (American Psychiatric Association, 2013), this is widely misinterpreted as a linear diagnosis that somehow reflects the 'functioning level' of the autistic individual rather than the idea of a 'constellation' (Fletcher-Watson & Happe, 2019, p. 40) of different profiles which represent this diversity more accurately.

### 6.4 Autoethnography as 'Autistext'

Autoethnography has been described as an emancipatory method that resists objectification (Richards, 2008), providing a 'socially-just and socially-conscious' (Ellis et al., 2011, p. 273) means of exploring issues around disability and difference. As an approach to research that allows for individual voices to be heard, it involves description and analysis of personal experience to gain understanding of cultural experience. Whilst autoethnography has been critiqued for being both biased and self-absorbed (Ellis et al., 2011), these arguments tend to come via

misunderstandings of the purpose of qualitative research. As such, Ellis et al. (2011) suggest that autoethnography ‘attempts to disrupt the binary of science and art’ (p. 283). In writing this chapter, I have considered ‘relational ethics’ (Turner, 2013) by obscuring the details relating to others who may appear in my writing. I am writing about my experiences because I have found comfort in the autoethnographic and narrative work of other neurodivergent writers, such as Yergeau (2018) and Ratcliffe (2020). Yergeau (2018) suggests that autistic stories, or ‘autistexts’, exist to ‘resist the cultural inscriptions that autism as a diagnosis suggests’ (p. 24), helping to complicate understandings of neurodivergence. Methodological approaches that involve self-narrative, such as autoethnography, can help to bring the lived experience of neurodivergent individuals to the fore, giving an author valuable control over their own narratives in the face of societal misrepresentation.

Neurodivergent lived experience is still misunderstood and misrepresented, in significant part due to the dominance of research located within scientific paradigms. In the work of Baron-Cohen (2010)—awarded a knighthood in 2021 for ‘services to people with autism’—autistic people across the gender spectrum have been depicted as having an ‘extreme male brain’ (p. 167) and a lack of empathy or theory of mind (Baron-Cohen, 2000). Elsewhere, a recent study sought to understand levels of social distress in autistic children by *causing* social distress in autistic toddlers and charting their ‘distress intensity’ (Macari et al., 2020). To counter the damage done by what Yergeau (2009) refers to as ‘the typical autism essay’, research that gives voice to neurodivergent people provides a counter-narrative. My experience of neurodivergence is a lived experience of being autistic, and therefore, this chapter largely focuses on this aspect. Although my diagnosis is only recent, I have lived experience of being undiagnosed autistic for more than 40 years. Whilst my own ‘autistext’ does not claim to directly represent anyone other than myself in terms of how being neurodivergent influences my life, I hope there is enough commonality to make it at least indicative of one dimension of neurodivergence.

## 6.5 NLS and Texts

An NLS approach allows for the mobilisation of broad understandings of literacy and text. Whilst traditional, ‘autonomous’ conceptualisations of literacy position it as a fixed set of skills, the ‘ideological’ perspective frames literacies as an evolving set of social practices, culturally located in particular contexts, manifesting in the relationships between people (Street, 2012). Literacies are not neutral but are subject to power relations, with some literacies being more ‘visual and influential’ (Barton et al., 2000, p. 12) than others. Literacies are also connected closely with the forming of identity (Wohlwend, 2009) with the concept of ‘identity text’ (p. 57) helping to demonstrate how identities are shaped by the consumption and production of texts. An expansive conceptualisation of text helps us to understand texts as written (e.g., letters, books, academic writing) but also as ‘multimodal artefacts’ (Pahl, 2007, p. 87) that encompass other modalities (e.g., songs, images, film).

What follows are three short autoethnographic reflections, coupling descriptive reflection with theoretical analysis. Each centres on a text or series of identity texts (Wohlwend, 2009) that helped me to shape and make sense of my own identity in light of an autism diagnosis received during a period of global disruption.

### 6.5.1 *A Letter: Language, Identity and Power*

I receive a letter from the Adult Autism and Neurodevelopmental Service. It states: 'To Whom it may concern. Christopher attended this service for assessment... The assessment concluded that they do a [sic] have an Autism Spectrum Condition'. This is a relief. The long diagnostic process was not so much a means to find out but to validate what I already knew. I had been working on the assumption that I was autistic for some time, so an alternative conclusion would have potentially led to feelings of uncertainty, self-doubt and shame even. The letter continues '[...] it is important to note that Autism Spectrum Disorder is a recognised disability under the Equity Act 2010 and as such "reasonable adjustments" should be made in any relevant setting'. I had received this diagnosis verbally a few days before, via video call with the psychologist. Nevertheless, there's something reassuring about these words appearing on paper.

This letter is not written *to* me but *for* me, to use when I require accommodations at work. Unfortunately, any accommodations I negotiated prior to formal diagnosis had been overtaken by the disruption of lockdown. Regardless, there's much contained in these short sentences, and this letter marks the end of a process of diagnosis that began with a doctor's referral 14 months prior. Although the typing error (the extra 'a') is a little jarring—arguably the most important sentence in this letter doesn't *quite* make sense—other aspects are more significant. This text has meaning for me in terms of my identity: how I see and understand myself. The letter refers to my diagnosis in multiple ways: as autism spectrum *disorder* (ASD) and autism spectrum *condition* (ASC). ASD is the terminology of choice in medical literature. The DSM-5 and the ICD-10, on which diagnosis is based in the UK, both frame autism as a 'disorder'—a word which evokes deficit, a brokenness. Deficit models prevail in all aspects of life. Since its inception, New Literacy Studies (NLS) has sought to challenge the 'deficit' model that stems from 'autonomous' conceptions of literacy (Street, 2012), where one dominant set of literacy practices are positioned as valuable, whilst the sociocultural, contextual and profoundly *meaningful* literacies of everyday life are sidelined. The 'ideological' (Street, 2012) model of literacy has sought to complicate binary notions of 'literate/illiterate' by questioning dominant discourses around literacy. Similarly, the neurodiversity movement has sought to challenge dominant understandings that position autism (and other minority neurotypes) as lacking against a default understanding of what it means to be human. The reframing seen in this letter, replacing 'disorder' with 'condition', is presumably an attempt to acknowledge the potential stigmatising effect of using particular language. However, whilst 'condition' is often used synonymously with

‘state of being’, there is also still something pathologised about the term. My response to this is more physical than it is intellectual—there is something slightly incongruous about a feeling of relief being associated with the confirmation of a ‘disorder’. However, being ‘disordered’ is something I’m increasingly happy to reclaim as a positive description.

There is a strong argument for using the term ‘identification’ rather than ‘assessment’ or ‘diagnosis’. Self-identification is considered valid by many in the neurodivergent community, due to the barriers to diagnosis faced by many. A referral for assessment in the UK requires agreement by a general practitioner (GP). As many in the medical profession still rely on outdated perceptions of autism, a referral will be rebuffed in many cases. Denial of access to assessment leads, in particular, to underrepresentation of diagnosis for anyone who does not present as male (Lockwood Estrin et al., 2020) or is part of a racial minority (Travers & Krezmien, 2018; Zuckerman et al., 2014; Ribeiro et al. (2017), and thus the system perpetuates itself and its ‘grave inequalities’ (Onaiwu, 2020).

My privilege as a white academic, with access, via my workplace, to a well-informed counsellor who could advocate for me, worked in my favour. These factors likely legitimised my request for diagnosis. Those who gain a GP referral face a lengthy wait, as UK diagnostic services are largely underfunded. In many countries, diagnosis is financially prohibitive. The process requires a significant amount of emotional labour, complicated by ‘bureaucratic literacies’ (Jones, 2014)—a flow of correspondence that requires reading and writing of letters and diagnostic forms. There is also the resulting stigma when diagnosis is achieved, and, in spite of autism being ‘a recognised disability under the Equity Act 2010’, for many, ‘reasonable adjustments’ will remain ungranted. I am conscious of the irony here of being a white man writing about underrepresentation. However, my motivation for sharing my experience is to use my position to highlight inequalities in the system and to strengthen cross-disciplinary ties with neurodiversity to ensure that diverse perspectives *are* increasingly represented in the future.

Back to my letter, another innocuous-looking turn of phrase also positions autism in a pathologising way. I am told that I ‘have’ ASC/ASD. This possessive phrasing uses ‘person-first language’, otherwise known as ‘non-disabling language’, which places ‘emphasis on the person first rather than the disability’ (Jensen et al., 2013, p. 46). This constructs me as a ‘person *with* autism’ rather than, as would be the case in identity-first phrasing, ‘an autistic person’. Autistic people, such as Sinclair (2013), disrupt pathological assertions about autism by suggesting that being autistic is not something that can be separated from the self—it is something that you *are*. The person-first language used in my diagnosis letter is now widely critiqued within the neurodiversity and wider disability study communities who suggest that person-first language has the potential to embed deficit understandings of disability. As Gernsbacher (2017) suggests, ‘desirable attributes are normally expressed through pronouns preceding nouns’ (Vivanti, 2020, p. 691), and therefore, PFL implicitly positions disability as undesirable. For these reasons, Botha et al. (2020) argue that the framing of autism through language ‘has material consequences for the autistic community, especially those who are minimally verbal’. Bottema-Beutel

et al. (2020) suggest that such framings have the effect of reinforcing ableist ideologies. The neurodiversity perspective, however, 'sees autism as an expression of cultural diversity, rather than pathology' (Vivanti, 2020, p. 691) and, therefore, the use of identity-first language asserts autism as an identity without presuming that this de-personifies the individual.

This letter, then, is an identity text invested with the weight of official discourse. This formal text has power to reinforce problematic medicalised conceptions of neurodiversity, reflecting the 'problem with power dynamics' in autism discussion (Yergeau, 2009). In recent years, however, the autistic community has itself sought to reframe discussions about neurodiversity using digital texts via blogs and social media. So when I read this letter, I do this having also explored autism more widely. On social media, the *#ActuallyAutistic* hashtag helps amplify autistic voices, adding detail and nuance that complicate the narrative around autism. Thus, this 'formal' diagnostic text does not exist in isolation, and the extended network of texts produced by autistic individuals has the power to recontextualise and shift discourses and personal understandings.

### 6.5.2 'The Schiphol Test': Affect, Assemblage and Movement

#### 'Push push push push... moving on...'

These words repeat in my head as I run. These are the words of a song, *Schiphol Test* by Underworld, playing through noise-cancelling earphones pushed deep into my auditory canals. Many autistic people process sound in ways that differ from the neurotypical population (Davies, 2019). For me, this results in a hypersensitivity to multiple environmental sounds which compete for attention and can lead to overwhelm. Headphones help me escape from complex soundscapes into a space where sounds weave in less challenging ways. Here, electronic beats and a repeating bass pattern accompany a familiar voice, all of which merge with the motion of my body through space as my trainers make their own rhythm on the asphalt. My hands, fingers splayed wide, make repetitive, jagged patterns in the air ahead of me in time with the beat. Driving synth base, repetition, movement, *flow*...

#### 'Got to get away...'

I rediscovered running in my mid-20s. I was put off most kinds of physical exercise as a child due to the shame involved in *always* coming last, compounded by the PE teacher who was overheard mocking my unusual running form. Running as an adult is a different experience. Since the onset of the pandemic, I have been running, compulsively, every day, because I need to. Amid reconfigured working and living patterns necessitated by new directives to prevent the spread of the virus, I have found multiple readjustments challenging. Like many autistic people, I find change difficult and rely on routine and certainty to keep myself calm. For most people, change and uncertainty has characterised lockdown. Disruption of routine. Distractions. All of these lead to overwhelm, which is characteristic of the autistic

experience of the world, particularly when the world feels as unstable as it does at this point.

*‘Connected to the soul...’*

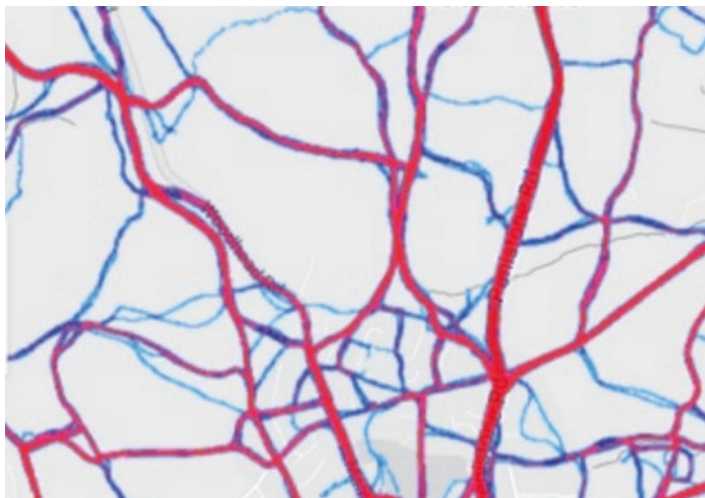
But running whilst listening to music helps me to find release. The song’s words become *my* words as movement helps me inhabit the space made by the song. The song is a text but one that is embodied and that I can move inside. As Frith (1996) suggests, music helps to define ‘a space without boundaries’ (p. 125). Running—movement—does not generally achieve this on its own: I need the music too. Not just this song, but this is one that has caught my attention during this time and one that I’m compelled to have on repeat. There is certainty in repetition. This does not feel like escapism—it feels like connection, as if the song is speaking *to* and *through* me. In particular, there’s something about the word ‘soul’ that chimes with my thinking round my identity and the fact that somehow my very essence has been disrupted and, concurrently, settled by my diagnosis.

Particularly at times of disruption or precarity, music has a powerful way of resonating. A connection is formed between the world, the song, and my body. I often rely on this process to help me escape a full meltdown. There’s a route I’ve discovered recently where, after a short section of residential roadway, a right turn takes me to the top of a hill. Reading the horizon, on a clear day, I make out the silhouettes of two coal-fired power stations 40 miles away. Soon after this expansive view, I’m led by the curve of the road, down a tree-lined hill into green fields inhabited by wildlife. I’m carried by this descent and the music and my surroundings, experiencing something close to joy, the opposite of the ‘emotion dysregulation’ (Swain et al., 2015) I was undergoing just minutes before. Running feels like creation, as if the energies flowing out of my body must be leaving some kind of trace. In fact, a digital record is being generated, by the GPS tracking on my watch. A map is produced, a line drawn that allows me to revisit my routes on my phone. As well as the individual map, it generates a ‘heat map’ of territory covered over a period of time. One such map (Fig. 6.1) shows my territory covered during 2020. Roads and paths most frequently charted are coloured ‘hot’—red and thick—whilst less common routes are marked ‘colder’ blue. The hill descent is the thickest red line on the map.

This map recalls a process developed by Deligny (2015) to map the movement (or ‘wander lines’ (p. 44)) of autistic children, charting a ‘mode of being’ (Deligny, 2015, p. 33) in the form of a network (‘the Arachnean’ [p. 33]). Deligny’s maps endeavoured to ‘shape a gaze in order to change habits’ (Ogilvie, in Deligny, 2015, p. 13), not to impose change on the observed individuals but to shift the gaze of the observer. The maps encourage the observer to identify value in places (or ‘modes’), where it may otherwise not have been evident. My own lines of drift are driven by affective experience—a map of territory covered in the pursuit of positive affective experience.

The recent turn towards ‘affect’ in New Literacy Studies (Leander & Ehret, 2019) understands text in relation to a body situated within ‘assemblages’ (Deleuze & Guattari, 1987) of material, immaterial, spatial, semiotic and environmental aspects. ‘Affect’ names the ‘prepersonal intensity’ (Shouse, 2005) that arises through the





**Fig. 6.1** Heat map

shifting from one bodily state to another—experiences that defy labels like ‘feeling’ and ‘emotion’ but take a powerful hold of our bodies and minds. This assemblage, involving running and song, features an affective ‘intensity’ (Deleuze & Guattari, 1987). In autism, the sensory self-regulation achieved through sensory means is often known as ‘stimming’ (Yergeau, 2018, p. 98). These self-regulatory autistic behaviours are, to advocates of behaviourist interventions such as Applied Behavioural Analysis (ABA), undesirable behaviours which should be suppressed. There is an abundance of studies looking at tracking and eliminating ‘stereotypic behaviour’ (e.g. Amiri et al., 2017; Tse et al., 2018; Zhou et al., 2020). Such studies deny individual agency over the body, seeking to deny the autistic need for sensory stimulation. This is the kind of perspective that would get me into trouble at school, regularly reprimanded for my facial tics that were interpreted as ‘pulling faces’. Recently viewing home videos from my childhood—visual texts that help me review and re-evaluate my own history in light of my recent diagnosis—it is clear that these behaviours were neither conscious nor confrontational. The DSM-5 Criteria (APA, 2013) allows that ‘many adults with autism spectrum disorder... learn to suppress repetitive behaviour in public’ (p. 54), and these movements are often masked due to the kind of social/cultural engineering that comes from wanting to appear ‘normal’.

The neurodiversity perspective reframes these movements as positive, empowering acts. Bakan (2014) explores the intersection between music and stimming, reframing self-stimulatory behaviour as ‘productive, communicative, pleasurable and even socially valuable’ (Bakan, 2014, p. 133), noting a ‘fluid progression between different modes of productive engagement.’ This productive engagement with multimodal texts, via music, has much in common with affective perspectives on literacies. Furthermore, just as the ‘ideological’ notion of literacy seeks to challenge the ‘autonomous’ idea of literacy as a pre-established set of skills—forcing

the individual to comply with state sanctioned and narrow conceptions of literacy—the neurodiversity perspective challenges the pathologised notion that there is a standard way of being, of *moving*, that the individual must adhere to. There is a concept of ‘autistic joy’, which has yet to permeate academic accounts of autistic experience but is often exemplified on social media. Whilst my experience of this active ‘reading’ of the song is about sensory regulation, it is also about the ‘autistic joy’ that comes from sensory experience of the world, and the assemblage of sound, movement and space feels profoundly generative.

### 6.5.3 *Special Interests: Photography, Aphantasia and ‘Seeing’ the World*

Another letter arrives in June. This is a summary of the discussions that led to my diagnosis, ordered under headings ‘Development and Social History’, ‘Social Communication and Interaction’ and ‘Sensory Experiences’. Comments here largely recount the challenging aspects of being autistic. The final section—‘Restrictive Repetitive Patterns of Behaviour Interest or Activities’—details what are often called ‘special interests’ (Jordan & Caldwell-Harris, 2012) that result in hyper-focus on particular topics. The form reports that I have ‘a tendency to spend long hours taking, developing, looking at and reading about photographs’. I love photography, and, particularly during lockdown, I have found comfort in 35 mm photography. Even this, however, is framed as a negative, ‘restrictive’ interest. As well as being a source of pleasure, absorbing interests also provide a way of making sense of the world.

I have been thinking, for instance, about the concept of ‘masking’ or ‘camouflaging’ (Livingstone et al., 2020) autistic traits in order to present as neurotypical. This thinking has involved using photography to explore my physical ‘stimming’ behaviours. This visual text (Fig. 6.2) is one attempt to examine my own ‘autistic’ movement. I shot and developed a sequence of stills capturing the motion of my own hands on black-and-white 35 mm film. The process of creating this text, as well as the text itself, assisted me in achieving some abstract distance from myself, creating a sense of space from the subject of my thinking, offering a means of thinking about the sensory self-regulation that I achieve through repetitive motion.

The fact that this text is visual, rather than written, is significant. Autistic people report differences in how they visually process and engage with the world. Grandin (2006), for example, reports a vivid experience of ‘thinking in pictures’. Others, like me, are at a different point in the visualisation spectrum, with a complete inability to think using internally generated pictures. Aphantasia (Zeman et al., 2016) is an inability to visualise using the ‘mind’s eye’, resulting in an inability to ‘see’ in visual imagery. I do not have the ability to visualise or remember objects, people or places by forming a mental picture of them. It is not possible to be formally diagnosed with aphantasia, but there are tools online to aid self-identification. There is



Fig. 6.2 Moving hands

little known about its implications but also less stigma involved than with other neurodivergent 'conditions'. Until very recently, I assumed that 'visualising' was just a metaphor for *conceptualising*, rather than an actual act that people could perform. Working through this idea, I created a comic to share on social media in an attempt to describe and communicate what aphantasia means for me (Fig. 6.3).

My use of photography and drawing could be explained as a method of *externalising* the process of visualisation, as a kind of extended cognition (Clark & Chalmers, 1998), helping to develop my understanding of my neurodivergent identity in a way that does not assume the primacy of language. Although I do not think *in* pictures, I find it useful to think *with* pictures. We still know little about how neurodivergent ways of being impact on thinking and learning. What is clear is that pedagogical approaches that make assumptions about how people think, learn and process information that assume a neurotypical default are not sufficient for everyone.

## 6.6 Future Directions

Above I have taken a personal approach to illustrate how personal storytelling can illuminate lived experience. I suggest that similar methods could be utilised in two ways: as tools to enable literacy researchers to look inwards to their own experiences and outwards in relation to others. For Smith (2016), storytelling offers a valuable counter to 'dominant disembodied research paradigms' (p. 183). With this in mind, I encourage literacy researchers to consider whether they could use autoethnography to exemplify their perspectives on the world, in relation to text and

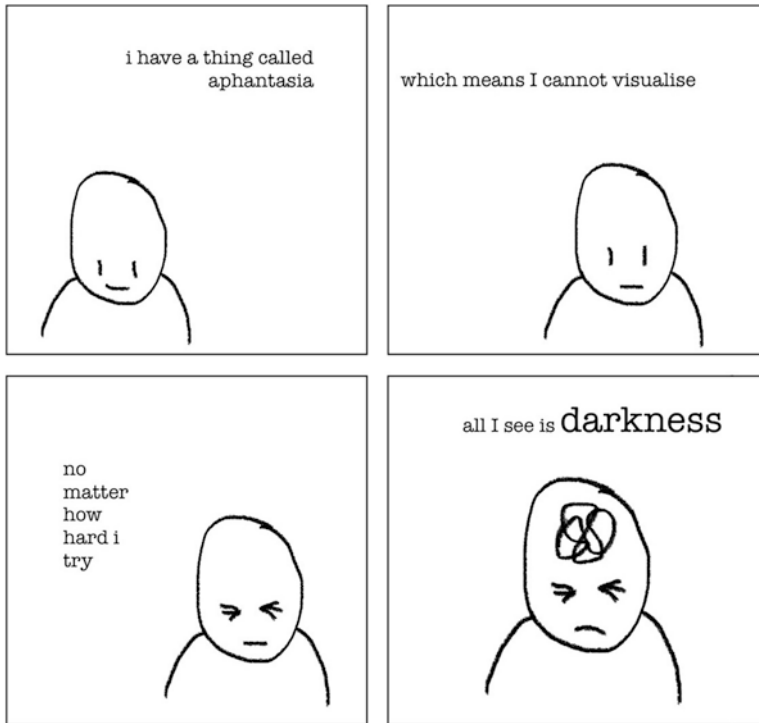


Fig. 6.3 Aphantasia comic

textual assemblages—especially those whose perspectives are currently underrepresented. Where self-storying does not feel appropriate, I encourage engagement with other storying approaches that seek to understand people’s lived experiences, particularly in relation to text, and how these intersect with neurodivergent identities.

I have also advocated for greater recognition of the diversity around individuals’ meaning-making practices, here in relation to multiple modes. When engaging with stories and texts in the ways suggested above, I ask researchers to continue to pursue the more ‘generous’ definitions of text afforded by NLS. I also suggest that researchers consider the roles that these engagements play in their own meaning-making, as well as those of participants. By forefronting sidelined ways of engaging with the world, literacy research has the potential to embolden its status as a force for shifting dominant, normative perceptions of worth.

In conjunction with these methodological moves, I also encourage literacy researchers to engage directly with work around the neurodiversity paradigm. Firstly, an understanding of neurodiversity would enrich researchers’ own understandings of the world and thereby feed into the discourse around literacies, in the same way that engaging with conversations around race, gender or socioeconomic background helps a researcher to understand the multiple intersecting factors that

shape lives. I have drawn parallels between NLS and neurodiversity, demonstrating how these ideas can be united to address coexisting concerns. Secondly, and more directly, this is to encourage further literacy research that allows for the voices of neurodivergent people to become increasingly present. As Murray (2020) suggests, 'people have different experiences of the world, and unless we listen to them when they tell us what makes their lives difficult and what helps, we often make things worse' (p. 105). Literacy research has a history of illuminating the lives of marginalised people, helping to shift traditional perspectives. A greater focus on the lived experience of neurodivergent people in literacy research would enrich society's understanding of the value of literacies and the nature of neurodivergence. We know that texts have the power to shape lives, both positively and negatively. By focussing on the texts around neurodivergent lived experience, there is an opportunity for literacy studies to further broaden the scope of its impact.

## 6.7 Concluding Thoughts

This chapter has called for the expansion of literacy research to take greater account of work around neurodiversity, as well as exemplifying the value of inclusive, narrative methodological approaches. My own story, demonstrating the impact of various texts, has addressed issues around neurodivergence, non-written communication, representation, cognition, affective experience, self-expression and identity. These texts engaged with dimensions of experience that include the sensory, the spatial, movement, meaning-making, power, learning and thought. Evidently, a single autoethnography by a white, male neurodivergent academic is not enough in itself: it is necessary to take account of the culturally and socially diverse nature of the neurodivergent population. I hope that my 'opening' is a hint at the possibility for future work.

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