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**Dancing with the daffodils: using a Shared Reading approach to explore autistic identity**

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**Note:**

*This is participatory research; all involved are 'insider' members of the autism community, and the project has been completed collectively. The use of inclusive first-person language gives equal voice to all involved and serves to negate any implication of duality between the researcher and the researched.*

**Editorial comment**

In this paper, the author questions the studies on autism which refer to deficits, with particular reference to an autistic individual's impaired ability to understand figurative language. Together with her autistic co-researchers, she challenges this notion by using a Shared Reading approach. Two poems were shared online with two groups (six parents of autistic children and six autistic adults). These poems were read aloud and discussion of the images and meanings that arose were shared and discussed further. The study shows that autistic people are very capable of taking meaning from the lines and relating this to their own experiences. In addition to questioning the conclusions of previous published studies, sharing the poems served as a catalyst to talking

about their lives and perspective. It also brings to mind a paper published in the GAP Journal in May 2021, written by an English teacher, Isabelle Finn-Kelcey, who felt her autistic students were down-graded because the examiners did not appreciate or understand autistic writing.

## **Introduction**

Since the early days of autism conceptualisation, we have been told that we struggle with figurative language (eg Happé, 1993; 1995). In this context, we take ‘figurative language’ to be the use of expressions that do not rely on strict meanings but instead create links between concrete and abstract ideas. Early investigation of the language of autistic children suggested that our interpretations are literal and that we struggle with features such as metaphor (Melogno et al., 2017). Faced with a sentence such as, ‘*skyscrapers are the city’s giraffes*’, it has been suggested that we will be unable to overcome the essential lie (skyscrapers are not giraffes) and will need help to translate the metaphor into a simile (skyscrapers may be *like* giraffes in certain features) and therefore understand the writer’s intention to convey the buildings’ height.

More recently, some studies have questioned the assertion that figurative language is universally affected in autism (Kalandadze et al., 2018). Where there is no language impairment, it is suggested, autistic people do not perform significantly differently in figurative language comprehension than typically developing peers (Kalandadze et al, 2022; Hermann et al., 2013; Norbury, 2005; Gernsbacher & Pripas-Kapit, 2012). The ‘language impairment’ concept within this will be returned to later in this paper, but the conclusion of these studies is that difficulty with figurative language is not an absolute feature of autism (Kalandadze et al., 2018).

It is a leap from acceptance that we may not be automatically ‘impaired’ regarding our use of figurative language, to support for figurative language to be used as a vehicle to investigate and communicate our lived experience and our understanding of our autistic identity. It is this leap that this paper endeavours to articulate.

### **The use of figurative language to explore and communicate our lived experience**

The underlying principle of this ‘leap’ is that our use of such language may for some of us be a powerful tool of expression. Indeed, seen from this perspective, many of the supposed examples of our deficits in this area might be reassessed as elements of the Double Empathy problem (Milton, 2012; Chown, 2014). The researchers who identify our deficits, if they are neurotypical, may be missing the autistic meaning being expressed, and have mis-attributed their mistake to our failure.

For example, in 2010, Gold et al., set out to ‘*examine whether a deficient semantic integration process underlies the difficulties in metaphor comprehension*’ of autism. They did this by presenting participants with paired words that were in some cases deemed by them to be ‘*unrelated*’. The autistic participants identified more pairs of words as related than did the neurotypical controls (Gernsbacher & Pripas-Kapit, 2012). As early as the first descriptions of autism, Leo Kanner identified that autistic subjects use ‘*poetical ... metaphors*’ (Kanner, 1946, p. 244) and this propensity has been recorded in multiple studies since (for example, Dereu et al., 2011; Gilchrist et al., 2001). A member of the current study shared how he calls a hat used to carry items (in the manner of a

bag) a 'will-power'. He traces this use to a children's book where the character was exhorted to 'use your will-power' to resist an assailant and subsequently carried items saved from the exchange in his hat. Although the word use may be built on a misunderstanding, there is no (other) word in English for a hat used as a bag; in a sense, therefore, will-power is the 'correct' term. It may be that the autistic participants in Gold et al.'s study were able to make more connections across words than their neurotypical counterparts through using their so-called idiosyncratic language skills (Gernsbacher & Pripas-Kapit, 2012).

### **The meanings conveyed between author and reader**

Such an ability to connect words in a way that conveys meaning is, in the study of literature, how '*a reader's environment, feelings and responses interact with the language of a text*' (Cushing, 2020 p. 131). This builds on Rosenblatt's work on Reader Response Theory (Rosenblatt, 1978), where the reader is seen as taking an active role in the creation of meaning from text, as a co-creator of that meaning with the writer. If the paired words supplied by Gold et al. had meaning and connection for the reader, according to this theory, then that meaning exists and should be seen as legitimate, genuine and 'authentic' (Giovanelli and Mason, 2015).

### **Support for the validity of autistic engagement with text**

Support for a belief that autistic engagement with text has validity, and that autistic understanding of language goes beyond conventional understanding of language impairment, is supported by Savarese's work with non-speaking autistic student, Tito Mukhopadhyay. Savarese argues that neurotypical reduction of language to 'mere meaning' (Savarese and Zunshine, 2014) misses

the potential that the same language may have for an autistic receiver. He recalls Mukhopadhyay's response to the reading of a passage aloud:

*Claude read.... I saw the voice transform into long apple green and yellow strings, searching under the table for who knows what? Threads like raw silk forming from Claude's voice. Claude read. I watched those strings vibrate with different amplitudes ... I watched those strings with stresses and strains, reaching their own elastic limits and snapping every now and then, when his voice reached a certain pitch. I saw those snapped strings form knots like entangled silk, the color of apple green and yellow.*

(Mukhopadhyay, 2011, pp 200-201).

Here both Mukhopadhyay's reaction to language and his use of language show atypical but vastly rich, inventive, creative and – arguably beautiful – responses. Yet Mukhopadhyay, being non-speaking, might be conventionally described as being 'language impaired'.

### **Aim of the study**

This paper presents a novel approach to articulation of the lived experience of autism, in that it encourages and supports the use of figurative approaches. We believe that what emerges from our pilot studies suggests an innovative way for autistic people to explore and share their perceptions of the world.

### **The sample**

Pilot study exploration for this approach took place through groups held online during 2021. Two pilot groups of six adults each spanned a period of six weeks. Nominally, the first group was for parents of autistic children (including adult autistic children), with the second group for autistic adults. However, it became apparent that there was significant blurring between the two categories. Most

of the 'parent group' also identified as autistic themselves, either formally through diagnosis, through self-identification or through exploration. Equally, some of the autistic adults in the second group were themselves parents of autistic children. We made the decision to include all of us together (including the 'researcher') as participant members of the autistic community.

## **The method**

The methodological approach for the study was that of Shared Reading (Billington et al., 2016; Billington et al., 2013; Billington, 2011), a strategy developed by the charity, *The Reader*, which involves using literature as a starting point for discussion. We shared two poems, read aloud by the researcher and then again by a volunteer member of the group, sharing the screen and following the text together. These were read slowly and experienced in 'real time', without prior preparation, facilitating immediate and personal responses. The poems were - '*I wandered lonely as a cloud...*' by William Wordsworth and '*Differentia*' by Emily Porter St John.

These readings prompted questions and comments as thoughts and memories emerged, scaffolded by what we heard (Longden et al., 2015). Members of the groups voiced connection that the poems made to their lives and to their perceptions of their autistic identities, with group members taking notes of both their own responses and what was said by others. These 'notes' took a variety of forms - written, mapped, sketched and even painted. These data were then drawn together into a written narrative, further shared and agreed by the group, which is presented here. We plan to present the more visual elements in an exhibition later in the summer.

## **Discussion**

We found that the texts, together with the shared identity and focus on autism, acted as a '*socially coalescing presence, giving a sense of both subjective and shared experience*' (as found by Dowrick et al., 2012 p. 16). Skjerdingsstad and Tangerås (2019) identify that in Shared Reading the '*boundary between text and dialogue about the text is permeable*' (p. 6) so that through the text we were able to explore our identities, challenges and triumphs, using the text as our shared focus. Notwithstanding that 'joint attention' is another area where we, as autistic people, are supposed to show deficit (eg Mundy & Sigman, 2006), the shared platform of the text provided a rich context for our explorations and discussions.

## **Capturing the voice of autistic people who do not use speech**

It is interesting that Skjerdingsstad and Tangerås (2019) identify '*both utterances and silences*' as being of value (p.6). There is a paucity of participatory research in autism that captures the 'voice' of those autistic people who do not use speech as their primary form of communication. In these pilots, all the participants were verbally fluent, but those of us who have been teaching online during the Covid pandemic will be aware of the power of the 'chat bar' to support communication. The method of working described in this paper may well be one that will enable participation by this neglected portion of the autistic community, and that is something that we are very keen to explore moving forward.

## **The understanding of ourselves and our autism developed through the poems**



The understanding of ourselves and of our autism as scaffolded by text using a Shared Reading approach is, in this paper, presented in response to the two poems by William Wordsworth and Emily Porter St John (see *Figure 1*).

**Figure 1:** The two poems

### **I Wandered Lonely as a Cloud**

I wandered lonely as a cloud  
That floats on high o'er vales  
and hills,  
When all at once I saw a crowd,  
A host, of golden daffodils;  
Beside the lake, beneath the  
trees,  
Fluttering and dancing in the  
breeze.

Continuous as the stars that  
shine  
And twinkle on the milky way,  
They stretched in never-ending  
line  
Along the margin of a bay:  
Ten thousand saw I at a glance,  
Tossing their heads in sprightly  
dance.

The waves beside them danced;  
but they  
Out-did the sparkling waves in  
glee:  
A poet could not but be gay,  
In such a jocund company:  
I gazed—and gazed—but little  
thought  
What wealth the show to me  
had brought:

For oft, when on my couch I lie  
In vacant or in pensive mood,  
They flash upon that inward  
eye  
Which is the bliss of solitude;  
And then my heart with  
pleasure fills,  
And dances with the daffodils.

### **Differentia**

Love for one's child  
is a spring  
bursting from strata of earth,  
garnered from sky-showers

Love for one's mate  
is a wild brook  
hurtling from rock to rock,  
pouring into deep pools.

Love for one's friends  
is a river,  
curving, full of reflections,  
tinged with calm colours.

Love for one's kind  
is an ocean,  
domed, tidal, wide as the sky,  
deep, deep below islands and  
shores,

maker of rain,  
of all streams,

of itself.

## Findings

### ***Comments elicited by William Wordsworth's poem***

We liked Wordsworth's use of the word '*lonely*'. We recognise the celebration that it implies, that alone-ness need not be negative. There is a contentment in being one's own self. The phrase '*bliss of solitude*' is particularly powerful, but it is also interesting that the poet, happy being alone, nonetheless draws joy from seeing the '*multitude*'. We felt that the daffodils were all together in a crowd '*like neurotypical people*'. The poet does not want to join the daffodils but still takes great pleasure from their dance. We recognise parallels in this, such as the enjoyment of standing alone at midnight on New Year's Eve and '*joining in*' through watching fireworks from other people's parties. There is a strength in feeling '*a part*' of the groups around you, even while being '*apart*'.

One of our group appreciates daffodils as being '*unapologetically yellow*', and we discussed the notion of why they might need to apologise for being what they are. We linked the movement of the daffodils '*dancing*' to tiptoe walking or our use of autistic flapping to release excitement or to relax. This is a strong image of acceptance of what is natural. One of our group suggested that this is their '*idea of bliss - wandering along, focusing on what I think is important*'. Another reported that they were late for an appointment that day because they had paused to watch a spider shedding its exoskeleton. One of us expressed our shared feeling of unfairness, asking, '*Why is this okay when a poet stops to look, but not okay for us?*'.

### ***The joy of monologues***

This prompted discussion of our joy of '*monologuing*', of narrating our lives in real time. Many of us reported this in our children, but many admitted to still enjoying giving an internal commentary as adults. It is, we agreed, a tremendous pleasure on those rare occasions when we can monologue aloud to an 'interested' party (and we agreed that the lack of interest felt by the recipient is irrelevant to that enjoyment!). Perhaps it is the opportunity to do just that in the poem that is prompting Wordsworth's heart to 'dance'.

### ***Comments elicited by Emily Porter St John's poem, Differentia***

We were interested in the metaphor of water in the poem *Differentia*, especially the concepts of reflections and hidden depths. There is a juxtaposition here of peace and turmoil in water, a combination that one of us captured through describing a river as 'tinged with calm'. There is a difference between the surface of a river and what is going on underneath, and – in the same way – we expressed some anger at the perceived need for autistic 'masking'. We shared outrageous comments we have had made to us by outsiders along the lines that we '*can't be autistic because...*', as if there is only one type of river and a trickling stream could not also be a torrent. One of the group reported being told by a neurotypical colleague, '*You are too much like me to be autistic*', and another was asked by a doctor, '*So, just how autistic are you?*'.

We wanted, if possible, to identify our differences as strengths rather than as hindrances, and when we did find ourselves expressing negative comments, these tended to relate predominantly to the neurotypical view of autism. Those of us who are parents of autistic children expressed our concern that others

might misunderstand our children if we support them to continue to act 'naturally' like the daffodils. We fear that older/other children will exploit or bully our children or may reject them. We do accept, though, that some elements of autism and some autistic behaviours are difficult. Our love for our children – the first element in *Differentia* – runs deep, is in the centre of all we are, but there is also a need to 'dig deep' to access it when we are exhausted. We love our children as autistic people, but do not necessarily love all their behaviours. These behaviours can be challenging, aggressive, frustrating, and it can be hard work to manage them. We know that this 'digging deep' that we do will not happen in wider society, and we fear for their futures.

### **Sensory responses to the two poems**

We are particularly interested in our sensory responses to the poems. For example, one of us responded instinctively to the word 'daffodils' that she '*loves red and green together*', a response which surprised others of us. We do, however, accept that we may experience our senses differently to others. Many of us report sensitivity to elements such as touch or to loud noises, and some report enjoyment of strong smells (especially our own!).

One of us shared that when they have their eyes closed and there is a sudden loud noise such as a door banging, they can see a flash of tartan '*...no, gingham*'. This may be different colours depending on the noise. They describe the sensation as being an '*after image*' of the noise. Many of us enjoy water, finding it calming and sensorily pleasing. Some report fearlessness of water which caused our parents concern and does so now for us for our own children.

One member of the group described how, as a child, they used to feel that they were looking at the world through a fish-eye lens. They had a visual impression of everything being contained, being drawn in and distorted, although this was pleasurable rather than distressing. We came back to Wordsworth's description his '*inward eye*'. We agreed that, as Wordsworth describes, our recall is particularly strong and may be visual, so that we can access past events almost like watching them again on film. One member of the group prefers to access through hearing, describing how living '*in his head*' is akin to having Spotify or an internet connection he can access internally. This member described their ability to recall lyrics, how they have many hundreds in their head which provide a rich inner anthology. Another recalled nursery rhymes recited by their father and internalized, and how this was how they first made sense of language. We agree that these tendencies can be an issue if negative memories get stuck in our loops, but we discussed how we have learned to edit the film or the soundtrack, and – with maturity – to discard it if it is not positive.

### **Images and words can distract**

A number of us have gravitated to the creative industries and feel that our different way of seeing things gives us strength. We can memorise in detail and deconstruct mentally, watching and revisiting ideas visually or aurally, and then making connections. These images or sensory issues can be a distraction, though. One member reported how, in the poem *Differentia*, saying that love of one's child is a '*spring*' conjured a coiled piece of wire, and that this image distracted them from the rest of the poem. Similarly, Wordsworth's assertion that there were '*ten thousand daffodils irked: had he counted them?!*' One member of the group reported being distracted by the smell of the daffodils during the reading of the poem. This member is very attuned to their sense of

smell, describing how they always knew when their daughter was becoming ill because they could smell it.

### **The analogy of water in *Differentia***

In general, we loved the analogy of water in *Differentia*, conjuring images of walking along a harbour. Although we cannot see them, we know that the river is teeming with fish. There is a fishing club on Thursdays where one of us lives, and all the fishermen are there catching different fish with different baits. We love the idea of variety and accepted difference. There are the same people, the same canal boats, walkers, fishermen; there is a feeling that there is something there for everyone. You can sit by the river on the bank and 'reflect' – look into the water and see yourself and also think about where life is going on its journey as the river meanders.

### ***Love and water***

We agreed with the motif that love as water comes in waves. It comes towards you then ebbs away again. Although it can be dangerous you can be held by water; it is cleansing and restorative, it washes the sand off your feet. It is spiritual, which brought us back to the act of washing as a symbolic act. We feel that a river is seasonal in the same way that a relationship may be seasonal. We do not necessarily want or need someone to be there all the time, nor to be with someone all the time. We describe our friends as those 'who remember with us'. We share very intense relationships with our friends. Through them we see our own relationships diffracted, given back to us - like in a broken mirror or reflection in a stream.

Some of us have had no experience of romantic relationships so are unable to comment on that aspect of *Differentia*. We do not know the expectation of a romantic relationship. However, if it is a 'wild brook hurtling from rock to rock' then that will produce spray, and through that spray, a rainbow. We capture that idea as our perception of romance.

### ***Love for one's kind***

We take '*Love for one's kind*' to be about kinship, about finding sameness through our autistic identity. We are all different, and we can get on with people who are not like us, but it is there – kinship. We feel that there is an element of recognition, of '*sameness*'. One member describes how they had '*quite simply only recently come into friendships*' through joining an autistic group and another discussed doing an MA in autism where most people on the course are autistic, as are the lecturers. We wondered if the few neurotypicals there are 'masking'? How, we wondered, will they cope?

### ***Being out and seen as autistic***

We agree on the importance, for those of us with the courage to be 'out', to be seen as autistic and to be open about it. One, a lecturer, described being a role model for autistic students. This openness has led to other staff members asking for advice about themselves and a general reduction on 'othering' of autism. Those of us who have come 'out' as autistic, report that most people were not surprised at the revelation, and that we are recognised by and recognise autism in our kin. Within our families we totally 'get' autism. We accept and are accepted. One member disclosed that their reaction to their

autism diagnosis was, *'Well thank goodness for that – there's nothing wrong with me then!'*.

### **Concluding comments**

Fiction, and particularly poetry, is a *'lie that helps us see the truth'* (Rolfe 2002, p. 89) that has the potential to extend our understanding of fundamental human pursuits (Smith et al., 2021). There are several 'truths' that, we believe, have emerged through our engagement with literature as our platform in this study.

The first is an absolute refutation that we are, because of our autism, deficit in our ability to make connections and to use figurative approaches in language to explore our experiences. We have relished the connections, the 'leaping off' moments, the personal insights and the shared identities that this project has produced. We have, to be sure, enjoyed our 'literal moments' (I particularly relished the question, 'Ten thousand daffodils – has he counted them?!'), but these have never been at the expense of abstract or metaphorical appreciation. We have seen the daffodils as neurotypical people, ourselves as the poet, the river as our lives and the spray as our potential romantic rainbow. We have savoured both the depth and breadth of the ideas we have shared.

The second is the portrayal of autism that has emerged through our shared consideration in this way. Too often what autism 'is' has been defined from the outside, by neurotypical adults defining the life chances of autistic children into adulthood through misconceived and sometimes erroneous theorisation. This study gives formal voice to just a few of us as immersed members of the autism community, to articulate lived experience of autism from the inside. Most of what we describe here is positive. We are not blind to the challenges, but autism is our *'normal'*, and we see no reason to bemoan our very being as not being like



that of (some) others. As our speaker who ends our discourse articulates, there is *'nothing wrong'* with us.

Lastly, we want to bring together the content and the method of this project. The voice of autistic adults discussing abstract and metaphorical connections is not commonly heard in research, not because of a deficit in us but because of a deficit in *perceptions* of us as perpetrated by the external research community. While the research community predicates that autistic people cannot use figurative language, or that we struggle with non-literal interpretation, it will not provide opportunities for our voices to be heard through these means in the research. Their perceptions of autism have become a self-fulfilling prophesy.

Through collaborative structures such as the Participatory Autism Research Collective (PARC), truly participatory autism research, including that supported by autistic researchers, is now starting to find a voice. As we work together to re-invent society's perception of autism, we must not be afraid to challenge the stereotypes and assumptions that have, for so long, restricted understanding. We believe that it is vital that we embrace a participatory model in autism research so that our first-person narrative continues to be heard.

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