

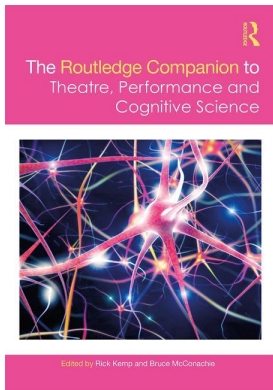
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## The Routledge Companion to Theatre, Performance, and Cognitive Science

Rick Kemp, Bruce McConachie

### Imagining the Ecologies of Autism

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Melissa Trimingham, Nicola Shaughnessy

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# IMAGINING THE ECOLOGIES OF AUTISM<sup>1</sup>

*Melissa Trimingham and Nicola Shaughnessy*

Autism is a prevalent theme in both literary and cognitive studies. There are numerous fictional narratives of the condition, many of which are written by non-autistic authors as well as autobiographical accounts of the experience, poetry by autistic writers, television, film and theatre representations (Grandin 1995; Hacking 2010; Semino 2014). The condition is also discussed in connection with key topics in cognitive science that include theory of mind, empathy, attention, intersubjectivity and emotion. This chapter draws upon insights from cognitive neuroscience, performance theory and practice, as well as our personal and professional experience of living and working with autistic people in order to better understand the characteristics of the autistic imagination.

## **Autism and the imagination**

Disability studies in the West have challenged the prevalent discourses on autism that stress deficits in need of remediation or cure, emerging from the medical model that underpins diagnosis. These new thinkers, often autistic themselves, demonstrate that autistic people are, in fact, 'neurodiverse' and communicate in distinctive ways that 'neuro-typicals' may not understand. Whilst social imagination has been identified as an area of difficulty in diagnostic criteria, there is increasing recognition of imagination as an area of 'difference,' as is evident in Bruce Mills's account:

With the increased incidence of autism and the insights arising from autists' self-reporting and artistic work...we might begin to re-think past paradigms that oppose typical/normal with atypical/abnormal creative processes. In the continuum that marks the different cognitive processes that produce 'art' we might begin to refine an understanding of the imagination in relation to autism...The nature of play- and its symbolic and imaginative dimensions- might vary in relation to the particular manner in which the 'player' processes the world.

*(Mills 2005, 131)*

Indeed, research by Bonnie Evans (2013) draws attention to changing definitions of autism through the history of diagnosis and the shift from excess to deficit in descriptions of the

imagination in autism.<sup>2</sup> A more nuanced and variable picture of imagination in autism is now emerging, with research on autistic creativity and studies of artistic self-expression, particularly in visual art, poetry and music (Roth 2008; Happé and Frith 2010; Shaughnessy 2013). However, more work is needed to understand and engage with the different languages of communication within the autistic population (see, for example, Savarese 2015, and the testimony of artist Amanda Balls<sup>3</sup>). Moreover, there has been recognition recently that autistic people physically perceive the world in ways that neurotypicals do not. Differently inflected senses can derive both intense pleasure and fear from objects, material form, light and sound. Naoki Higashida, in *The Reason I Jump: one boy's voice from the silence of autism*, describes this: 'Sometimes I actually pity you for not being able to see the beauty of the world in the same way we do. Really, our vision of the world can be incredible, just incredible' (2013, no pagination). The 'beautiful otherness of the autistic mind' (Happé and Frith 2010) can be infused with pain and confusion. As Higashida describes it, 'the detail...claims our attention, and then our hearts kind of drown in it, and we can't concentrate on anything else.' Higashida describes sensory confusion: 'It's as if my limbs are a mermaid's rubbery tail'; and when noise surrounds him, 'it feels as if the ground is shaking and the landscape around us starts coming to get us, and it's absolutely terrifying.' This confusion comes about because autistic individuals may have 'hyper-' (over) or 'hypo-' (under) sensitive modalities of touch, hearing, sight, smell and taste (Bogdashina 2003). They also have an eye for detail that is far more sensitive than neurotypical perception, leading to joy in repetition and fascination with tiny details ('stimming'). As Happé and Frith point out, 'repetition is not repetition...if you have expert levels of discrimination' (2010, xvii).

The authors of this chapter have themselves undergone a journey of changing understanding through our lived experience of bringing up our own autistic children, and also through our work as theatre researchers. Using creative, practical and embodied performance approaches, informed by cognitive neuroscience and in collaboration with psychologists, we have discovered more about the characteristics of the autistic imagination, realising how rich and full that inner life might be, and becoming sensitive to the problems that everyday encounters can cause for this population. This interdisciplinary research takes place in the context of an increasing recognition of the potential of the arts as a key to exploring thinking and feeling states (perception, engagement, emotion), and the encouragement of individual agency in those with autism in order to improve health and well-being. Psychologists are using creative methods as research tools, acknowledging the value of arts practices for developmental science: 'a current wave of methodologically rigorous studies shows the depth of arts learning, as well as how arts engagement can be harnessed for transfer to other skills' (Goldstein, Lerner and Winner 2016, 1505). Hence, it is stated that 'developmental psychologists cannot afford to ignore such a developmentally entwined experience as the arts' (1505).

### **Imagining Autism: a novel approach**

The case study for this chapter, 'Imagining Autism Drama, Performance and Intermediality as Interventions for Autistic Spectrum Conditions' arose in the context of collaboration between the arts and sciences.<sup>4</sup> The use of the term 'intervention' in the title is itself a contested term between the communities of practice engaged with the project. As Scott Kaufman says, 'perhaps the problem isn't with the interventions but with the whole model that presupposes a normal' (2017 <http://behavioralscientist.org/rethinking-autism-social-awkwardness-social-creativity/>). Matthew Lerner, a psychologist who uses drama as a research tool (Socio-Dramatic-Autism Research Interventions), has developed skills-based

methods using drama to enhance social communication and social interaction in working with students with Asperger syndrome. Lerner suggests a potential paradigm shift:

...what emerges from the research is that rather than think about the task of understanding social cognition of people on the spectrum and also how to treat them, teaching them to behave in a way that better approximates the way other people are doing it, it becomes more incumbent on us to understand people on the spectrum, and meet them where they are, and really try to understand how they are experiencing a situation. What are the skills, features, tendencies, passions they are bringing to the table, and how can we use those to make this social world they seem to want to access? How can we make it accessible and rewarding?

(Lerner in Kaufman 2017, no pagination)

Crucially, Lerner suggests, in a statement indicative of the shift in autism research from a medical to a social model of disability: 'Instead of viewing people with ASD as "socially awkward" individuals who need to be "fixed," we should instead conceptualize them as *socially creative*. They may not do things the "right" way, but they do them their way' (Lerner in Kaufman 2017, no pagination).

Imagining Autism was a project defined in the context of the field of applied and socially engaged theatre, referring to theatre adapted for work in social, educational and community contexts intended to have a therapeutic or educational purpose. Within this field, the terms of reference are also being contested in relation to the 'social turn' (Nicholson 2011; Shaughnessy 2013). In this case, the original aim was to use drama as a means of producing efficacious and beneficial effects for autistic children through their participation in activities that engaged them socially, physically and creatively. Psychologists and theatre practitioners worked together, initially with psychologists evaluating the work, and theatre practitioners designing and delivering the exercises. As the work developed, however, the research design was adapted, moving towards a 'transdisciplinary' practice, engaging bi-lingual vocabularies whereby the disciplinary perspectives informed and impacted on each other to create new approaches (Shaughnessy 2017b). The team worked in three schools with three groups of six to eight children, aged 7–11, with a diagnosis of autism. The intervention involved participants in weekly drama sessions (45 minutes) in a portable tent (described as the 'pod'). Each week the participating children experienced a different themed visual and sensory immersive environment: forest, underwater, outer space, the Arctic and under the city. The environments offered imaginary worlds presenting a magical multisensory playground of light, colour, sound and moving images, where trained practitioner/performers interacted with the children either as themselves (as friendly guides) or using puppets and masked characters; they conjured storms (sound, light and a soft plastic sheet rising and falling lightly over the children), sunny woodlands (birds singing and dappled light) or a moon-scape (ultra violet light). They shared a loose narrative with the children (structured as a journey), encouraging speech, movement and creative expression (including humour, building on autistic children's interests in slapstick). Whilst the pod functioned as a container, the 'way out' was always clear, and practitioners could follow a child into the school hall and play there if preferred. There were several features distinguishing our approach as 'novel,' a term used by the psychologists within the project and by subsequent commentators responding to its outcomes (O'Sullivan 2015). The project may be described as a 'counterpoint to mimesis'; its methods draw upon contemporary performance practices and 'post-dramatic' paradigms which are non-illusionist and in which practitioners and materials draw attention to the performative

nature of the activity. This means the work is based on a particular mode of pretence with participants and practitioners aware of themselves as co-creators of fictional constructs. This contrasts with drama practices based on social scripts and skills-based learning. It also flattens the hierarchies between performance creators, facilitating practitioners and participants. The pod is a space in which we were able to work together through a process of mutual discovery. The awareness of the ‘not real’ also involved an ‘in the moment’ mode of engagement, requiring spontaneity to improvise, following the children’s cues without recourse to scripts or habits as a process of ‘becoming’ in the making of meaning. The environments also stimulated a high level of sensory arousal, in contrast to the low arousal learning environments recommended for teaching autistic children. Whilst this caused some concern with teachers about whether the participants would cope with this level of sensory stimulation, the positive outcomes indicated the potential value of short-term exposure to highly stimulating sensory approaches.

As drama specialists and applied theatre practitioners, we might be charged with ‘applying’ drama to a perceived ‘problem’ (the autistic inability to communicate); interacting with the children as the other, from our neurotypical cognitive base; and intending to bring about an improvement in the children’s ‘condition,’ which psychologists would test and prove.<sup>5</sup> We suggest that the project’s sub-title ‘Drama, Performance and Intermediality as Interventions for Autistic Spectrum Conditions’ reveals the quantum shift in our own understanding since the small pilot project in 2010 when we first began to build our immersive and interactive environments – the calming green forest, white Arctic landscape and blue underwater worlds. The word ‘interventions’ was troubling for us at the time, but the psychologists we were working with persuaded us that this was the terminology recognised in research contexts for the participatory performance practices we were planning. The intervention, however, has stimulated a transformation of understanding, affecting the researchers as much as the researched.

The holistic process that subsequently took place inside – and outside – the pod or performance space was a changing ecology of material form, people and affect that changed child, practitioner, teacher, sibling and parent. Vibrant, responsive materials and objects in our environments changed all whom they touched physically – and those whom they touched more indirectly. The autistic community has its own culture that meshed inextricably into the neurotypical cultures that we as practitioners and researchers brought into the pod; far from this being a discrete aesthetic experience contained within the pod, wider cultures of education and the family were similarly enmeshed and permanently recast. The sensory and interactive elements were designed to help participants develop felt understanding through experiential, physical and immersive media. The training methods emphasised the importance of play, turn-taking, liveness, open space, physicality, improvisation, shared attention, responding to the other, reading non-verbal cues and working as an ensemble. The participatory and process-based approaches emphasised autonomy and authorship, offering a license to play creatively (the importance of play is an aspect which is often overlooked post-diagnosis). The psychologists established proof of concept that the methods positively impacted upon language, social interaction, empathy and imagination (Beadle Brown et al. 2017). Although the intervention was of a low intensity and duration (45 minutes per week for one term), statistically significant changes were recorded in several areas of deficit and across the spectrum. The biggest changes were in reciprocal social interaction, emotion recognition and the severity of autistic symptoms as rated by parents and teaching staff. However, significant improvements were also found for at least some of the children in socialisation, communication, imagination and play, with at least some children from all

three schools showing improvements in at least one area. The research collaboration also led to unexpected insights into the imagination in autistic children, demonstrating how it is differently inflected from the typically developing child, particularly in terms of visual and auditory perceptual processes, awareness of time and space, physical and verbal modes of creative expression and responses to objects and interactive media.

A developing body of work is now building evidence of the effectiveness of drama as a means of engaging with and improving outcomes for autistic people (O'Sullivan 2015). Examples include the UK-based actor and director Kelly Hunter's 'Hunter Heartbeat Method,' which uses Shakespeare's language to interact with autistic children across the spectrum, an approach that has been positively evaluated by Ohio State University ([www.kellyhunter.co.uk/ohio.php](http://www.kellyhunter.co.uk/ohio.php)). This is also a sensory and play-based method, emphasising creativity and being 'in the moment' as co-producers of participatory performance: 'These games are derived from Shakespeare's poetic exploration of how it feels to be alive, specifically through his obsession with the eyes and the mind and with reason and love; how we see, think and feel, which forms the spine of his poetry throughout the whole canon' (<http://kellyhunter.co.uk/shakespeares-heartbeat/the-hunter-heartbeat-method/>).

### Cognitive perspectives

Because engaging in practical drama activities benefits participants, a key term in connection with drama and autism is experiential. This learning through doing is an embodied practice, and the cognitive turn in theatre and performance was one of the core theoretical perspectives informing the development of the Imagining Autism approach (McConachie and Hart 2006; Lutterbie 2011; Kemp 2012). Cognitive theory spoke to our experience as drama practitioners and as parents; we knew that using the multimodalities of participatory performance and play-based approaches (working with puppets and objects), physical interaction, auditory stimuli (soundscapes, musical triggers, microphones) and visual and haptic materials (e.g. costumes, hats, torches) could elicit communication, shared attention and sustained interaction. Participatory performance (with interacting auditory, bodily, temporal and spatial elements) is a means of accessing cognitive processing, helping us to understand how autistic children perceive and connect to the world around them. Play-based practices within multisensory creative environments are a scaffolding for meaning-making and learning. The approach can be conceived in terms of cognitive ecologies, through its engagement with three ecologies, those of the environment, social relations and human subjectivities. The idea of ecologies, encapsulated in the title of this chapter, as interconnected landscapes of cognition, is taken from Edward Hutchins (1995), but Trimmingham has also used this metaphor in connection with new materialist interpretations of the pod environment in Imagining Autism (Trimingham 2017). The ecological framework is also the conceptual underpinning for participatory performance praxis (Shaughnessy 2012; Harpin and Nicholson 2017): Harpin and Nicholson use terms that resonate with the practice-based research methodologies of Imagining Autism, referring to participatory performance as 'affective encounters, [that] bring together the sentient with the spatial and environmental' in a 'dance between the affective agency of environments, social relations and subjectivities' (7). Trimmingham's background in professional theatre and interests in phenomenology complemented Shaughnessy's work on language, gender identity and autobiographical performance. Shaughnessy's initial interest in mirror neurons via Rizzolatti (2009) was in the context of her son's diagnosis, leading to her earliest writing on theatre, cognition and affective neuroscience, whilst Trimmingham came to this body of work through a perceptual route in her studies of

Merleau-Ponty in relation to the Bauhaus. Significantly, modernism was also a shared interest for both authors as this was to become a feature of what we conceptualise as an aesthetics of neurodiversity (Shaughnessy 2017a).

As our work has developed and in dialogue with other theatre and performance scholars, we use '4 E' cognition as a conceptual framework. Rhonda Blair and Amy Cook (2016) offer a particularly useful summary of this model which provides a way of encompassing some key aspects of how to connect performance and theatre to cognitive science. Cognition, they explain, can usefully be seen as embodied, embedded, extended and enacted, each stage claiming slightly more for the imbrication of selfhood and environment.

Embodied – cognition isn't separable from our physicality.

Embedded – cognition depends heavily on off-loading cognitive work and taking advantage of affordances, or potentials, in the environment.

Extended – cognition extends beyond the boundaries of the individual organism, encompassing aspects of the social, interpersonal environment.

Enacted – cognition is inseparable from action (and is often an outgrowth or even an attribute of action).

In *Imagining Autism*, we described our approach in terms that refer to the interactions between participants and the following core elements that map onto the 4 Es:

- 1 Physical (embodied) through non-verbal communication using movement and clowning, informed by Richard Hayhow's 'mimetics, a psycho-physical practice (Trowsdale and Heyhoe 2015), and Phoebe Caldwell's intensive interaction.<sup>6</sup>
- 2 Immersive (embedded) through the multisensory 'pod,' the tent-like container housing the themed scenic environments, with loose material elements acting as triggers or affordances.
- 3 Participatory (extended) through interaction between practitioners and peers using improvisation, turn-taking, copying, call and response.
- 4 Play (enacted) through the playing out (action) of loose narratives in which autistic children pretend they are experiencing the various journeys to the forest, arctic, outer space, under the sea and under the city.

However, there is a related feature at play here, situated within the 'inters' of the interdisciplinary, interactive and intermedial, a third space beyond dualisms in which there is shared understanding of cultures, languages, perspectives. Through drama, we enter into an empathic and relational understanding of how self and other are interdependent. As Harpin and Nicholson have summarised in their introduction to *Performance and Participation*, these practices are informed by an understanding of 'how different forms of participation are reshaping questions of agency as relational practices rather than individualised acts' (Harpin and Nicholson 2016, 13).

Fundamental to the project's approach has been a focus on empathic engagement with autism as difference and the use of drama as a means of tapping into the experience of perceiving differently. This is a basis for our training methods, the 'walking in another's shoes' exercises that draw upon our experience of working with the autistic community to enable professionals, families and carers to 'imagine' the experience of another through creative practice. Playing with puppets, finding your clown and experiencing the world from different perceptual perspectives are some of the practical approaches developed by

the project team for training practitioners as well as being disseminated through workshops for teachers and care-workers. The team have worked with as many as 60–70 staff in a single workshop, exploring different ways of engaging with space, objects and people. In developing our practice-based training methods, we aimed to do three things:

- To develop performance training systems and vocabularies appropriate for practitioners to work with autistic people
- To free practitioners from habit, enabling them to respond in new and original ways to stimuli and to be open to play
- To engage in imaginative and empathic dialogue with autists.

Just as trained musicians can find jazz improvisation difficult, so the devising methods used in contemporary performance practice involve making material with new vocabularies that can be challenging to practitioners experienced in traditional approaches to training. In many respects, the practitioners needed to be self-abnegating, to free themselves to respond in new, non-typical ways to these encounters with difference.

### **Relational practices and new materialisms**

For an autistic person whose senses are differently tuned to the world from neurotypicals, the pod was a space of improvisation, liberated amidst a wealth of different materials, where participants were free to play and reveal their intense sensory worlds to those of us willing to learn. Let us take Matthew, one of the participants at one of the schools, as a case study. He was cautious in his first encounter with the pod, running in and out of the forest in week 1, but playing happily with the mole character outside the pod in the school hall. Matthew had very limited speech when the project began; in week 2 (outer space), he discovered the microphone and began to play with his voice, exploring different registers (his voice was breaking) through a form of sound and word painting. By week 5, the Arctic, he had progressed rapidly:

The microphone, we have speculated, changed Matthew's relationship to his voice, making him aware of its potential as an instrument for self-expression. His voice was breaking and he experimented with the different registers, playing with the sounds of words through a form of onomatopoeic sound painting that sounded like descriptive scene setting, even though the language was emergent as he produced a range of speech sounds rather than words, with a story telling intonation. We could trace a developing grammar as the changing intonation (rising and falling) of repeated single words (most frequently "space") created holophrastic sentences. Matthew's demonstration of communicative intent (rarely seen before according to parents and teachers), and the sense making processes that are articulated through language give some insight into his cognitive and perceptual processing as well as his developing [...]awareness of those around him. Meaning is being constructed through the integration of visual, acoustic and bodily modalities. We see him thinking physically as he moves around the environment, in between the episodes on the microphone, using a torch and a moon rod puppet as an extension of his arms. On the microphone, his voice is the exploratory instrument and as the project progressed his language developed from a rhythmic rhyming rap in the Arctic setting to a poetic meditation in one of the final sessions, uttered from a cardboard tube that functioned as a pretend microphone in the underwater



environment: ‘Now I see the world, don’t let it change the past.’ This was adopted as the subtitle for the film, as Matthew became the project’s performance poet.

*(Shaughnessy 2017b, 499)*

Matthew also enjoyed wrapping himself up protectively in the blankets, covers and cloths in the pod; he was gradually coaxed out of these wraps by a mischievous puppet pulling at his blanket, a naughty husky dog running away with it and a friendly snowman taking his side and defending him against the ‘thieves.’ Together, Matthew and the snowmen chased them away. Through simple material means (puppets, blankets, a microphone) inside the pod, Matthew was led into interaction with others, so that outside the pod, in the classroom and especially at home, he began to speak. He made observations on the weather to his mother, for example, and commented that the car was driving unusually slowly in the snow (‘Mummy, the car is *dead!*’), communicating to his mother and to his teachers for the first time that he was noticing the world around him.

In one school, the children we worked with were diagnosed with autism but were exceptionally able verbally. It was obvious, however, that they had problems relating to their peer group and making friends, whether this took the form of excessive withdrawal or over-exuberance and controlling behaviours. It was this group that showed the greatest gain in empathic skills following the project. Watching the filmed documentary footage of the sessions gives the clue as to why this might be so. These children were constantly playing together, for example, in the chaos of storms at sea, freezing to death in the Arctic (whether by bad weather or the evil of the Ice Queen), in the forest launching spontaneously into the game ‘What’s the Time, Mr Wolf?’ (with fully costumed Mr Fox instead of a wolf) or protecting the woodpecker in the Arctic (who had been sadly blown off course when migrating to Africa!) from being eaten by a hungry Inuit. There was absolute freedom to play, even to the extent that Greg (noisy, excitable and often in rivalry with his peer John for control) burst a hole through the cloth roof of the pod and announced he could see a ‘sabre toothed tiger!’ There was not much left of this roof section by the end of the session, but there was no harm done, just the release of an extended fantasy that all the children then joined in. Later, Greg took over the job of protecting the woodpecker, holding him closely and taking him to places of safety, and Joseph, a very quiet child, in his session also took over this role. Two other children, before even entering the pod, dressed up as two polar bear cubs, ‘blood brothers’ (they announced), and they sustained this role throughout, both getting up to rough and loud mischief, but controlled from their worst excesses by the Inuit. In the other group, two children were also dressed up as mischievous furry animals throughout the piece; the Inuit called them ‘puppies’ and trained them by tempting them with fish.

A sense of humour pervaded much of the improvisation in every session of the pod, usually slapstick physical humour that often provoked loud laughter. The snowman, for example, lay ‘sunning’ himself on a lounge in the Arctic and when he got up, Joseph slipped into his chair. The snowman, of course, pretended not to notice, immediately covered Joseph with a white cloth – and ‘sat’ down. He sprang up in surprise, much to Joseph’s delight; and of course, in true clown spirit, the snowman immediately repeated the joke several times over, to even more delighted laughter from Joseph. This is a space of improvisation, of learning through play and interaction, a space that is vital to cognitive development. These spaces of play and learning have been characterised by anthropologists Tim Ingold and Elizabeth Hallam as spaces whose aim is not to ‘project future states, but to follow the paths along which such projections take shape’ (Hallam and Ingold 2007, 15).

In the words of Katherine Hayles, ‘Materiality, like the object itself, is not a pre-given entity but rather a dynamic process that changes as the focus of attention shifts’ (Hayles 2012, 14). The focus of attention or consciousness is moreover only a fraction of neurotypical thought. The unconscious is a ‘perceptive capacity that catches the abundant overflow too varied, rich and deep to make it through the bottleneck of attention’ (ibid.). But the abundant overflow is not too varied, rich and deep to escape the attention of an autistic child whose eye for detail is often sharp and defined, and their ‘bottleneck of attention’ is often much larger than that of other children’s. Researchers and practitioners in *Imagining Autism* were drawn into the shifting ecology of autism through the objects, materials and environments they inhabited temporarily alongside the autistic children. So began a ‘cultural’ exchange between the participants, that is the children and the practitioners. The ‘abundant overflow’ also began to seep out from the defined place of performance into the surround, that is, the ‘[s]paces produced through networks of social interactions’ (ibid.), those spaces of classroom, school, family and community.

The impact of these relatively short but intense encounters is evident in the following extracts, which are taken from parental reports (interviews and questionnaires) by the psychologists in the post-project assessment which took place three to six months after the project finished. (All children’s names have been changed.)

He started saying things he never said before. I am flabbergasted by the amount of language. Every time I wrote down something was the day after *Imagining Autism* and it continues.... The big changes came from *Imagining Autism* and not from school. The biggest change is that he now comments – e.g. “medicine’s empty”. He loved the sessions. School said he would skip along the corridor to go there.... He has gained confidence and the ability to communicate more. He is now having a conversation. Before I would ask and get a minimal answer.

Another parent wrote:

He said things like “car was taking alien eyes off”, “bell was ringing the alien was crying” and started to make expressions on his face. He commented on feelings which he has never said about...For the first time in his life when he plays figures are talking to each other and he is making up a story. Imaginative play with toys is a breakthrough. He started to play with related toys after sessions e.g. space toys...He has gained in his imagination, he is talking more, commenting on everything. He is identifying emotions, and naming them. He gave me a kiss and a cuddle which is very rare. He is reasoning things out – we had a conversation for 15 minutes for the first time.

In this anti-Cartesian geography of play, cultures do not collide but they intermingle and imperceptibly transform. In the cultural and social context of the pod, performing objects, puppets and materiality itself served to cross boundaries and articulate new realities.

### **Participatory futures**

*Imagining Autism* was developed at a time of change in autism awareness and diagnosis, with the autistic community increasingly giving voice, stressing the importance of community-based participatory research models, advocating research that has relevance to the lived experience of autistic children. Whilst autism research outputs have doubled in

the twenty-first century, with similar increases in funding, the priority has been ‘basic science,’ with only 5% of research reported to have been dedicated to support and education (Pellicano 2017). As stated in *A Future Made Together* (2013), for the most part ‘advances in research fail to impact upon those who need them most: autistic people, their parents and carers and those who help support them’ (Pellicano, Dinsmore and Charman 2013, 4). Historically, decision-making in research has rarely involved the autism community.

The importance of engaging autistic artists as actors in media representations has been foregrounded through productions such as the National Theatre’s stage version of Mark Haddon’s novel *The Curious Incident of the Dog in the Night-time* (first performed 2012). Engaging autistic practitioners in the design and delivery of *Imagining Autism* has been critical to the project’s development. A series of outreach events in educational and community settings have been informed and supported by a developing network of autistic advocates. At a 2017 residency at The Atkinson, a leading arts centre in Southport, UK, the team were joined by an autistic self-advocate and practitioner, Annette Foster, who immeasurably enriched both the encounters with participants and the training offered to parents and teachers. Her experience concludes this chapter.

The future for *Imagining Autism* is imbricated in these communities of change. Karan Barad’s terms ‘intra-action’ or ‘complex manifold of connections’ (Barad 2007, 388) can be used to describe both the ‘pod’ environment of the 4 Es in action and the tangled debates within the autistic community of which we are necessarily a part. In our understanding of autistic children, we have travelled, we hope, a very long way from our earliest interdisciplinary endeavours. We hope that the project, and those outside it, will be able to respond flexibly and imaginatively to the challenges that lie ahead, as understanding of autistic people as different, imaginative and with their own strengths continues to grow, enriching and transforming an increasingly neurodiverse world.

We conclude with the words of Annette Foster, a live artist whose PhD explores autism and gender identity through performance.<sup>7</sup> As an autistic artist associated with the project, she offers her perspective on *Imagining Autism* as an advocate of the autistic community, in dialogue with the authors of this chapter:

NS/MT: You have described the *Imagining Autism* pod as an ‘autistic space.’ As an autistic person, can you explain how you perceive the environment?

The *Imagining Autism* pod is an Autistic Space because the children who are invited into the pod are allowed to be their autistic selves. The oppressive nature of living in a neurotypical world is lifted for those 45 minutes they are in the sensorial immersive environments. They are encouraged to be themselves and relate to the world in their own way. No one tells them not to stim, not to touch that or not to sit there. They are free to explore the space from their own unique perspective and develop relationships with objects, puppets and people in the space. It is a safe, all-encompassing space, an opportunity to play without judgement. Practitioners are discouraged from correcting and directing and are trained to follow the children’s direction of play. This might be by copying the words or sounds they make, by playing with objects in a certain way or encouraging an exploration of touch. The pod is a multiple sensorial space geared towards people who are drawn to sensory stimuli, for example, glow in the dark rocks, large space rocks covered in bubble wrap, a microphone, shadow puppets screen, video projection and various puppets. Characters in this space are verbal or non-verbal, encouraging children to communicate in whatever way they feel comfortable. The make-believe world becomes a space where autistic children can be free.

I was involved in *Imagining Autism* as a practitioner in 2017, and for two weeks I played the role of the alien, operating a Bunraku puppet. It felt oddly appropriate as I have always felt like an alien, having been diagnosed with Autism six years ago, at the age of 39. As the alien, I have large white eyes and a globular head that I move around a lot trying to reach the children in some way. They seem to like me. I touch the world with white scratchy bulbous fingers that are very good at pointing and waving. I have long stretchy legs that can extend to make me a tall alien (if I like), but most of the time I sit on the ground so that I am on the human children's level, as they are the ones I am most interested in. I hide in outer space, behind the shadow wall, in the glowing dark, waiting for them to arrive. I am nervous, scratching my head with my white gloved hands and checking that I have my moon rocks in place. I rearrange my spaceship, various planets and stars ready for take-off. I hear the children board the rocket ship and take off. I wait in anticipation with my sparkly bag in tow, in this dark extravaganza of an intergalactic cosmos filled with space rocks that I love to eat.

The human children arrive and I am excited as well as nervous about meeting them, wondering whether I will be able to relate to them, in this strange world we create together. I slowly emerge as the alien on the shadow screen, first waving at the children. My main mission on this planet is to find and eat rocks. I like the greeny yellow ones and hate the orange ones. I am obsessed and rope the children into finding rocks for me. If I don't like one I let them know with a loud 'Yuck.' I don't speak human only alien but most of the children understand my language fluently in a few minutes.

Although I've never done puppetry before, I've been a performance artist for the last 20 years and knew what was needed to do this work. I use my skills of being in the moment, taking cues from the children to interact, react, make mischief and be playful. I feel free to be my autistic self when I follow the children's lead. At parties, I was always the person drawn to children or animals and children rather than doing the 'small talk' with adults. Children are easier to read and also more genuine, they say what they mean and they do what they say. I like that. I find children much more open and accepting of difference than most adults. With most children, you are either instantly accepted for who you are or they will be direct with you and ask you questions about your difference, which I don't mind as once you answer their questions they accept it.

MT/NS: In your encounters with autistic participants when you worked as a practitioner on the project, do you feel your interactions were distinctive? How far did the project's training inform your approach and how far were you drawing upon personal experience to co-produce the activities?

I think my interactions with the autistic participants were unique. I am autistic, I relate to these children, I understand them in a way that possibly neurotypical people don't. This is instinctive. I see stimming as something that is needed to survive in a neurotypical world rather than something to be corrected. I understand from my own life experiences that autistic children are often misunderstood or not listened to. They are told that their way is wrong most of the time. Or at least this was my experience as an undiagnosed autistic child. Autistic people, especially late diagnosed people, are very good at copying, figuring out the rules of the neurotypical world. I understand intuitively how to connect with autistic people: stop, look, listen, pay attention to detail, copy and then, once you understand how, to, play with them, show you understand their world.

The project training informed my approach to an extent as it reminded me what I do instinctively as an autistic person and it allowed me to be myself during the training experience. I felt as if the training was quite freeing; people were training to take a journey into

the autistic universes, the individual universes of autistic people, all unique and complicated, as all autistic people are different. The training gave validity and legitimacy to the autistic experience for the first time in my life. It was a very unusual experience to be with neurotypical people learning about the autistic experience and how to communicate with autistic children. I felt I was in a room of people learning how to speak a language close to my own. I was being taught things I already knew instinctively, but perhaps, had never been articulated in this way. I was aware of my position as a spokesperson for the autistic community, even though I am only one perspective and can't speak for all. However, if I felt something didn't feel right, I could call it into question and help the team to understand what to tweak to make it more authentic or inclusive.

NS/MT: You have a professional background as an artist and as a performer; do you think that being an autistic person is a factor in your creativity?

I am an artist first and foremost. My work over the years has been an eclectic mix of performance, live art and visual art. It has always been autobiographical informed by feminism, identity, gender, sexuality and difference. However, for the last two years I've been working on a creative project as an autistic self-advocate, and this led to my PhD and performance practice becoming research as means of enquiry into and articulation of autistic identity. There's a misconception that Autistic people don't have imagination. As a late diagnosed autistic person who is also an artist, this is something I am challenging in all that I do! If you look at my website (nettypage.com), for example, it clearly shows I have an imagination and that I have built a whole career around my creativity as a multidisciplinary visual and performance artist. Autism researchers often refer to difficulties with 'social imagination.' I like to think of it as just a different social imagination from an autistic perspective, which is how you imagine other people and social situations. One of the problems with the stereotypes of autistic people lacking imagination, being maths and science wizards or male brained, is that it reinforces our obsession with binaries and categories: male/female, typical/atypical, normal/abnormal systemising/empathising. This doesn't take into account the complexities of neurodiversity. I resist being defined in terms of the medical model and want autistic people to be understood as different, rather than deficit. As a late diagnosed person on the spectrum, I have a unique experience of the world and this has been conveyed through my creative work throughout the years. So, I would say that I am an artist first, and then an autistic person.

## Notes

- 1 Part of this chapter was first published in *Applied Theatre Crossings*, an annual journal in Chinese and English edited by Cariad Astles and Xiaoxin Wang.
- 2 The first reference to autism is attributed to the Swiss Psychologist Eugen Bleuler who used the term in 1911 in his study of schizophrenia to describe social isolation and withdrawal into a fantasy world (its etymology is from the Greek *eaftismos*, meaning 'self-enclosed'). Leo Kanner and Hans Asperger developed new terminologies and understanding of the condition. Both use the term autism but refer to different characteristics. Kanner's work is associated with what came to be regarded as 'classic' autism (in which individuals are profoundly affected by what was later defined as the 'triad of impairments' in communication, social interaction and social imagination). Asperger, however, describes the higher functioning manifestation of the condition, associated with individuals who may be highly verbal but have difficulties in social interaction due to what has been referred to as a 'systemising' brain. In the 1970s, Lorna Wing's revolutionary work replaced the black and white paradigms of Kanner and Asperger with the multi-coloured concept of the condition as a spectrum of behaviours and features. See Wing (1996) and Frith (1991).

- 3 See 'In my Language' by Amanda Balls, [www.youtube.com/watch?v=JnylM1hI2jc](http://www.youtube.com/watch?v=JnylM1hI2jc).
- 4 Imagining Autism was funded by the UK's Arts and Humanities Research Council. Based at the University of Kent, the researchers were Professor Nicola Shaughnessy (Principal Investigator, Drama), Dr Melissa Trimmingham, (Co-Investigator, Drama), Professor Julie Beadle-Brown (Co-investigator, Tizard Centre for Learning Disability) and Professor David Wilkinson (Co-investigator, Psychology).
- 5 Children were assessed using the Autism Diagnostic Observation Schedule (ADOS), Vineland Adaptive Behaviour (VABS), cognitive measures, parental and teacher ratings, observation, interviews and practitioner ratings. The results were summarised thus by the psychologists:  
At the immediate follow-up, all 22 children improved on at least one measure. Of the 6 who improved on ADOS social interaction scores, 5 also improved on three or more other measures. Among the other measures, the most significant changes were seen in the number of facial expressions the children recognised. 4 out of six children maintained the changes in social interaction on the ADOS at 3 months post intervention with three showing maintenance at 9 months. All children maintained or showed increased changes in emotion recognition at follow up – between 5 months and 1 year after post intervention. The majority of children maintained these improvements at follow-up (between 5 and 12 months post intervention)  
Julie Beadle Brown/David Wilkinson speaking at *Imagining Autism: Exploding the Myths*, 21 March 2014, held at The Gulbenkian Theatre, Canterbury.
- 6 See [www.phoebecaldwell.co.uk](http://www.phoebecaldwell.co.uk) and Caldwell film (2010), 'Autism and Intensive Interaction,' Jessica Kingsley.
- 7 Annette Foster is a professional live artist undertaking a practice-based PhD at the University of Kent: 'Autism, Performance and Identity: Articulating Women and trans/nonbinary people experience of Autism through live art and performance.'

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