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Trimingham, Melissa and Shaughnessy, Nicola (2016) Imagining the Ecologies of Autism. Applied Theatre Crossings . (In press)

DOI

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Document Version

Author's Accepted Manuscript

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Imagining the ecology of autism

Melissa Trimingham and Nicola Shaughnessy

'Imagining Autism: Drama, Performance and Intermediality and Interventions for Autistic Spectrum Conditions' was an Arts and Humanities Research Council funded project based at the University of Kent (October 2011-March 2014). Investigators were Professor Nicola Shaughnessy (Drama), Dr Melissa Trimingham (Drama), Dr Julie Beadle-Brown (Tizard?) and Dr David Wilkinson (Psychology). Participating Schools were St Nicholas School Canterbury (Spring term 2012), Laleham Gap, Broadstairs (Summer Term 2012) and Helen Allison School, Meopham (Autumn Term 2012). The schools covered a wide spectrum of ability. The project has generated evidence that drama can impact positively upon the symptoms of autism. The research has also challenged many of the myths surrounding the condition, offering new insights into the imagination in autism.

Imagine a child who does not communicate verbally, does not engage in eye contact, meaningful interaction with their physical environment, families or peer group, and who apparently displays no imagination. Imagine a child engaging in repetitive actions such as rocking, hand flapping or spinning, seeking sensory stimulation through head banging and tasting non-edible items (pica). Imagine a child locked in their own world. This is classic autism, an enigma which continues to frustrate, frighten yet fascinate. Yet this condition is not 'beyond remediation' (Baron-Cohen et alia: 2009). This article is the story of a cross-cultural exchange, perhaps better described as a mutual imbrication, between the 'neurodiverse' community of autists and the 'neurotypical' communities most of us inhabit. Autism is a lifelong condition that has been recognised predominantly in the West, through a changing series of definitions developed in the fields of psychology and psychoanalysis (Evans: 2013). The first reference to autism is attributed to the Swiss psychiatrist Eugen Bleuler (1950 [1911]) who used the term in his study of schizophrenia to describe social isolation and withdrawal into a fantasy world. It is derived from the Greek words "autos"

meaning self and “eafismos”, meaning ‘self-enclosed’. Autistic thinking in Bleuler’s account is equated with an excess of imagination and hallucinations arising from the desire to escape from reality (Evans 2013:4). Autism continued to be associated with childhood schizophrenia until the middle of the century when the psychologist Leo Kanner published his paper ‘Autistic Disturbances of Affective Contact’ (1943) describing some children’s inability to form social relationships, based on observations of self, focusing on children in his clinic. In 1944 Hans Asperger, an Austrian paediatrician, identified an autistic variant in his account of a different type of child, one with a more mixed profile of difficulties and abilities. ‘Autistic psychopathy’, meaning autism (self) and psychopathy (personality disease) - which would subsequently become known as ‘Aspergers Syndrome’ - was characterised by Asperger as involving difficulties in empathy and forming friendships, as well as one-sided conversation, obsessive interests, limited eye contact, unusual gait or clumsy movements and an absence of humour. Such children, however, exhibited enhanced language abilities and were referred to by Asperger as ‘little professors’ because of their ability to talk about their favourite subject in great detail. Whereas Leo 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’s work describes the higher functioning manifestation of the condition. This is 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 second half of the twentieth century, Anglo-American definitions of autism continued to shift through reformulations that were linked to diagnostic categories, rather than observing individual behavior. Debates about causes and treatments proliferated, including the controversial and discredited ‘refrigerator mother’ theory of the 1960s, which suggested that autism was attributable to a lack maternal affection as well as the practice of removing children from the

care of their families and sending them to institutions for ‘mental defectives’ (Evans 2013:5). The closure of these organisations, at least in the UK, as the century progressed, led to initiatives from parental advocacy groups to develop new treatments that could be used in home and school environments and new research into the causes of the condition. These developments accompanied shifting understanding and approaches in the disciplines of child psychiatry, psychology and psychoanalysis moving away from a psychoanalytic approach (that sought to determine the causes of autism) towards an understanding of what autism is and how it manifests. In the 1970s Lorna Wing’s revolutionary work replaced the black and white paradigms of Kanner and Asperger with the multicoloured concept of the autism as a ‘spectrum’ of behaviours and features (Frith 1991, Wing 1996). At the severe end of the spectrum children may have no speech and at the more able end (‘Aspergers Syndrome’) children are very verbally able but find it hard to communicate and relate socially to others.

Worldwide¹, autism is not nearly as recognised and understood as it is in the West and even European countries vary widely in their diagnostic and treatment services. In China autism was unknown to most until relatively recently (Volkmar 2006) which means that diagnosis may be relatively rare. Moreover, the vast majority of tools² used to diagnose autism are created in the West and are open to interpretation so may not be appropriate for or adaptable to different cultural contexts.³

¹ The authors are grateful to Hannah Newman from the University of Kent for this summary on international perspectives on autism, from her research on ‘Drama interventions as a means to aid the diagnostic process of Autistic Spectrum Disorders’, (doctorate due to be submitted in 2017).

² For example, Autism Diagnostic Observation Schedule (ADOS) is considered as the ‘gold standard’ of diagnosis in the West.

³ For example, lack of eye contact is considered a key autistic trait but in some cultures eye contact is considered impolite in some circumstances.

After over a century of recognition and diagnosis, albeit within ever changing parameters of the condition, autism in the UK is subject to various ‘interventions’ that nevertheless demonstrate only limited success. This may often begin with behavioural approaches such as Applied Behavioural Analysis (ABA) when the child is very young. Initially associated with the work of Ivor Lovaas and the understanding that behaviour could be modified through teaching, the “Lovaas method” as it was originally known, had controversial beginnings as it was associated with aversives to punish inappropriate behaviour, as well as rewards for positive performance. ABA has become an established (and tested) treatment appropriate for use in the home and school settings. It is skills-based, working through trials that are taught and repeated in one-to-one sessions between a child and a specially trained therapist before being generalised in ‘naturalistic’ or ‘real life’ (i.e. not clinical) settings. Children are taught a range of social, academic and practical skills that equip them for schooling. In the USA, the method is approved and is used most frequently in children under the age of five. Other approaches such as the “Son Rise” programme or Stanley Greenspan’s ‘Floortime’ work which uses a child-centred perspective, encouraging an ‘alongside’ and ‘working with’ approach rather than skills based or simulated ‘how to’ techniques that model socially appropriate behaviour. These approaches are sometimes presented in opposition but can engage in productive dialogue as complementary approaches. This has been the foundation for the development of drama-based approaches to interact with autism, as it is recognised that drama can be both a means of modelling or rehearsing for interactions in the social world as well as being a means of facilitating self-awareness and self-expression for children with autism. Drama can be a tool to help the autistic population overcome their experience of isolation to connect with and locate themselves within the social world.

Education in the UK has been influenced by the models from the USA and similarly concentrates on developing essential skills for independent living but has had limited success for those severely affected. Less mainstream interventions such as Phoebe Caldwell's 'Intensive Interaction' approach, involving somatic and embodied approaches (physically-based encounters) have reported remarkable results. However, like the artists, performers, musicians and painters who work with autists of all ages and report similar successes, the evidence base is anecdotal and has not been subject to scientific evaluation. A developing body of work is now building evidence of the effectiveness of drama as a means of engaging with and improving outcomes for children with autism (O'Sullivan 2015). Examples include Matthew Lerner's USA-based SDARI (Sociodramatic Affective-Relational Intervention), a drama-based social skills programme for teenagers with Aspergers Syndrome, using improvisation games and theatre training techniques specifically adapted for people with Autism Spectrum Disorder (ASD) (Lerner et alia 2011); Kelly Hunter, the UK Director and actor, who has developed 'The Hunter Heartbeat Method' using Shakespeare with autistic children across the spectrum, which has been positively evaluated by Ohio State University⁴; and UK based 'Imagining Autism', the focus of this paper, a performance-based programme for children with autism which was scientifically evaluated as positively impacting on communication, social interaction and empathy, the core features of the condition.

Imagining Autism: Drama, Performance and Intermediality and Interventions for Autistic Spectrum Conditions' is a mode of 'applied theatre'. This term refers to theatre adapted for work in social, educational and community contexts and which will have a therapeutic or educational purpose. In this case, the aim was to use drama as a means of producing efficacious and beneficent effect for children with autism through participating in activities

⁴ <http://www.kellyhunter.co.uk/ohio.php>

that engaged them socially, physically and creatively. Psychologists and theatre practitioners at the University of Kent (UK) worked together: psychologists evaluating the work, and theatre practitioners designing and delivering the exercises. The project worked in three schools with three groups of 6-8 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 drama session children experienced a different themed visual and sensory immersive environment: Forest, Underwater, Outer Space, the Arctic and Under the City. The 'way out' was always clear, and practitioners could follow a child out into the school hall and play there if they preferred it. The team created imaginary worlds presenting a magical 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 and encouraged speech, movement and laughter.

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 autists themselves, demonstrate that autists are, in fact, 'neurodiverse' and communicate in distinctive ways that 'neurotypicals' may not understand. Many lead full and imaginative inner lives but more work is needed to understand and engage with their different languages of communication (see Saverese 2014, and the testimony of artist Amanda Balls⁵). Moreover, there has been recognition recently that autists physically

⁵ See 'In my Language' by Amanda Balls
<https://www.youtube.com/watch?v=JnylM1hI2jc>

perceive the world in ways that neurotypicals do not. Autists' differently inflected senses can derive both intense pleasure and terror from objects, material form, light and sound. Naoki Higashida in *The Reason I Jump*: one boy's voice from the silence of autism tells us: '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' (Q32, no pagination). The 'beautiful otherness of the autistic mind' (Happé and Frith: 2010) is often 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: (Q28) 'It's as if my limbs are a mermaid's rubbery tail'; and when noise surrounds him (Q27) '...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 autists often 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 article have themselves undergone a journey of changed understanding through our lived experience of bringing up our own autistic children, but also through our applied theatre work, discovering 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 cause those with autism.

We are both drama specialists and applied theatre practitioners. We might be (and were in certain circles) accused of '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 prove⁶. We suggest that the project's sub-title 'Drama, Performance and Intermediality as Interventions for Autistic Spectrum Conditions' betrays the quantum shift in our understanding that has taken since a 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 holistic process that subsequently took place inside - and outside - our '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, 'cultures' outside the pod were similarly enmeshed and permanently recast - cultures of education and the family.

The sensory and interactive elements were designed to help participants develop 'felt' understanding through experiential, physical and immersive media. The approach emphasised

⁶ 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*, 21st March 2014 held at The Gulbenkian, Canterbury.

the importance of presence and 'being' (rather than acting) as a means to work intuitively and creatively. 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 multi-sensory environments were highly stimulating (in contrast to the prevalence of low arousal learning environments for autism), whilst the participatory and process-based approaches emphasised autonomy and authorship, and offered a license to play creatively (the importance of play is an aspect which is often overlooked post-diagnosis). Psychologists were able to establish proof of concept that the methods positively impacted upon language, social interaction, empathy and imagination.⁷ The research is leading to new understandings of the imagination in autistic children and how it is differently inflected from the neurotypical 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. Understanding autism in terms of difference, rather than deficit, is in accordance with the social model of disability.

A further element of this practice-based research was the collaboration with the film artist, Sarah Turner, to create an experimental film documentary exploring the imagination in autism.⁸ The film, like the project, 'refashions' and 'extends' the world to explore the

⁷ 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.

⁸ Sarah Turner is an experimental documentary film artist whose work includes explorations of memory, identity, fiction and autobiography in *Perestroika* (2010) and *Perestroika Reconstructed* (2013). The film 'Now I See the World' is available from the

phenomenology of the autistic experience. 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. Playing with puppets, finding your clown and experiencing 'the world upside down' are some of the practical approaches developed by the project team for training practitioners as well as being disseminated through workshops for teachers and careworkers. The team have worked with as many as 60 to 70 staff in a single workshop, exploring different ways of engaging with space, objects and people.

In developing our practice-based methods, we aimed to do three things:

- To develop performance training systems and vocabularies appropriate for practitioners to work with autism
- 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 autism

Just as trained musicians can find jazz improvisation difficult, so the devising methods used in contemporary performance practice involve making materials 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.

Routledge Performance Archive:

<http://www.routledgeperformancearchive.com/search/video/1554>

For an autistic whose senses are differently tuned to the world from neurotypicals, the pod was a space of improvisation, a liberation of material wealth, where they were free to play and reveal their intense world of sensory pleasure and pain to those of us willing to learn.

Matthew for example at first would not enter the Forest scene in the pod (week 1) but played happily with the Mole character outside in the school hall. Matthew did not speak when the project began; but in week 2 (Outer Space) he discovered the microphone and began to play with his voice. By week 5 the Arctic he was performing poetry out loud, with the microphone, to all of us listening and responding to him. 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 all had a diagnosis of 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. All of them needed to develop their empathy; and it was this group that showed the greatest gain in empathic skills following the project. Watching the footage 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), spontaneously in the Forest launching into the game popular with Western children, '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 in rivalry with his peer John for control) burst a hole through the cloth roof of the pod (in a lowered end section) 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 laughter out loud. 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:14). 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’ 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, i.e. 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:14), those spaces of classroom, school, family and community.

The impact of these relatively short but intense encounters is evident in these extracts in feedback from parents as part of the qualitative evaluation measures. ‘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.’⁹¹⁰

‘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.’¹¹

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

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⁹ All children’s names have been changed.

¹⁰ These comments are taken from parental reports (interviews and questionnaires) to the psychologists in the post project assessment which took place between 3-6 months after the project finished.

¹¹ See previous note.

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