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Do You See What I See? Arts, Science and Evidence in Autism Research

Nicola Shaughnessy

In 2015 Arts Council England (ACE) launched a new research grants scheme, 'Valuing the Arts', articulating its priorities for evaluation that placed emphasis on demonstrable quantifiable impact. An explicit objective within the scheme was a funding-driven impetus towards ever-greater interdisciplinary research collaborations between arts and sciences. The role of the grants programme was stipulated as 'providing us with *evidence* to better *understand* the *impact* of arts and culture' (my emphasis – Arts Council England 2015). These priorities are consistent with those of other funders, similarly calling for robust measures and advocating the methodological rigour of empirical approaches as a means of establishing value in the arts. However, there are differences and tensions between these terminologies. Evidence of impact, as discussed in the case study presented in this chapter, does not necessarily equate with understanding *how* and *why* a creative practice generated change for participants. Moreover, how we establish value, and the different agendas between disciplines, are further considerations that complicate evidence, knowledge and impact equations.

The relationship between arts and science paradigms within such research collaborations is the focus of this chapter, which refers to a project that I led from 2011 to 2014, involving a team of psychologists and drama specialists engaging in research on autism (www.imagingautism.org). While arts practices are established as a means of enhancing public engagement with science, they also function

increasingly as methodologies, generating qualitative data to measure audience response, participant engagement or change in applied work (e.g. in health, education and community contexts). However, while serving as a useful tool for science, questions remain about the intrinsic function and value of arts research in interdisciplinary collaborations. As Levinson, Nicholson and Perry suggest:

If creative encounters between the arts and sciences are to be both playful and rigorous, they will not only dissolve the parameters of each, but they will inspire curiosity by gathering insights from different perspectives. (2008: 22)

This chapter will explore how, in the specific context of neuropsychologies, the scientific stance of observation and measurement is enhanced through arts-based approaches that offer opportunities to engage and interact, creating knowledge through collaboration that is arguably not possible through the science on its own.

Blinded by science?

In 2011 the Arts and Humanities Research Council (AHRC) awarded funding to a project based at the University of Kent, 'Imagining Autism: Drama, Performance and Intermediality as Interventions for Autistic Spectrum Conditions' (iA). The proposal was commended by reviewers for its rigorous and innovative interdisciplinary methodology whereby psychological measures were used to evaluate the benefits (or not) of a weekly drama workshop programme for participants (22 children with autism, aged 7 to 12 years). The application summarized the research approach as follows:

The project uses drama techniques as an intervention for autism to facilitate language and communication, sociability and empathy and imagination and creativity. The proposed intervention is designed to help autistic children to compensate for their difficulties through

participation in fictional structures in visual and sensory environments using, for example, puppetry, light, sound and multimedia. ... The project uses psychological approaches to evaluate the impact of the intervention [... it] will use measures of theory of mind, imitation, emotion recognition as well as ... ratings by parents and staff of attention, social engagement, communication and play-based activities.¹

The blending of arts and science is evident in the language of the application as well as its mixed-methods approach. The arts researchers had been somewhat uneasy about terminology, particularly the instrumentalist connotations of the term ‘intervention’, which might imply a *doing to* rather than *working with* approach, as is increasingly advocated in applied theatre contexts (Jackson 2007). We were advised, however, that in the context of autism research, the term has particular significance, indicating a therapeutic approach and that what we were proposing would be most accurately described, understood and hence funded, if represented in this way. As practice-based researchers working in education, social and community contexts, we were similarly cautious about the term ‘therapy’, being mindful and respectful of the tradition of drama therapy with training and practices grounded in psychotherapy. The inclusion of a drama therapist on our advisory board ensured dialogue between these distinct approaches. Differences between disciplinary vocabularies and priorities (including, for example, what counts as evidence, process vs. product, inclusion and reliability) are factors that can reverberate as hidden subtexts, occupying the spaces between disciplines, where the ‘inter’ risks becoming ‘counter’ to a project’s productivity. We became increasingly aware of disciplinary language differences, necessitating clarification, footnotes in publications and the development of bilingual understanding for transdisciplinary research. Ultimately, a series of blind spots was generated, and it was the process of realizing these and finding ways to overcome them that would lead to some of the deepest insights.

While the risk of bringing a neurotypical perspective to autism research might be deemed an issue to at least be aware of, in the case

of this project I suggest the converse was the case: our arts–science hybridity ironically reflected autistic perception and the detail-processing style whereby ‘thinking often becomes entangled in leaves while missing the forests’ (Klin and Jones 2007: 15). We were so focused on the detail of the research questions, outcomes and behaviours of the autistic participants that we risked losing sight of some features of context and process.

The focus for psychologists, in delivering the evaluation, was on quantifiable and reliable data to establish any change in the participants through measures that were based on impact on autistic symptoms. This included improvements in social-communicative, interactive and imaginative skills in accordance with the ‘triad of impairments’ in autism (Wing and Gould 1979) and the diagnostic criteria in use at the time.² Reflecting traditions of arts advocacy, it was noticeable that the arts researchers seemed more concerned than the psychologists to achieve a ‘positive’ result, seeking evidence to validate the method as efficacious. For the psychologists, however, a key objective was the feasibility of the research design, given what they referred to as the ‘novelty of the intervention’ and evidence that might signal potential to justify a larger scientific study. A checklist for assessing feasibility identified four dimensions:

1. process (recruitment and retention, missing data, assessor blinding, interrater reliability, willingness of children to engage);
2. resources (time and human/physical infrastructure);
3. management (e.g. ‘unexpected changes in the intervention’);
4. scientific (data outcomes, potential effect and sample size needed for a clinical trial).

In practice, satisfying these dimensions meant working within the constraints needed to reduce variables so that there was a clear sense of a method (here the intervention itself) being consistently applied to rigorously evaluate participant response. A pre- versus post-intervention comparison was used with the testing of adaptive behaviour, cognitive

functioning and emotional recognition.³ While the data produced indicated statistical evidence of cognitive benefit, the process provoked occasional tensions between different disciplinary perspectives.

For example, the intervention consisted of five scenic environments (Forest, Space, Arctic, Underwater, Under the City) rotated across a ten-week programme. These were contained within the 'pod', a portable tent-type structure, containing lighting, sound and multisensory stimuli appropriate to each setting (e.g. a leafy forest floor in Forest, a sandy beach in Underwater). The discovery by the psychologists that there was variability in the sequencing of these environments, with the order determined through participant considerations, created a serious methodological problem that potentially contaminated the evidence. From an arts perspective, the variations felt necessary, such as the decision to use Forest as a calming low-arousal introductory environment for the sensory needs of participants in School 1 in contrast to Space being the first-week workshop for the excitable boys in School 2. Similarly, programming the final Arctic workshop as a winter-wonderland December session in School 3, and hence shifting Under the City to November, set off some cross-disciplinary fireworks as the responsive and intuitive arts-practice-based approach threatened to undermine the controlled conditions needed for experimental rigour in scientific investigations. For the purposes of sampling, the psychologists had assumed that Week 1 workshops would be the same in each school and that, when the sequence was repeated after half term, the order and content would be identical. When it was explained that the second trip to each environment would be different to the first (building on what happened in the earlier workshop and offering variety), there was further concern about variables with the Arts PIs required to produce detailed plans for activities in each setting and an explanation of changes in the return journey. Assessor blinding meant data were entered anonymously and analysed in a random, counterbalanced fashion so that changes in sequencing could have implications for reliability.

Ultimately, it was understood that while the scenic environments changed, the methods were consistent with practitioners using similar techniques to interact with participants (Shaughnessy 2016). When the data were unscrambled (to see the results sequentially), the results indicated developmental progression from the start to the end of the programme across a range of measures (but not all, as discussed below). This analysis was conducted with the objectivity needed to be sufficiently robust to qualify as evidence that could be reported in scientific journals.

Different concepts of evidence, particularly in terms of the qualitative and quantitative, necessitated some bifocal adjustments to our cross-disciplinary lenses to achieve shared vision. Two further examples will serve to illustrate this.

Qualitative and quantitative dialogues

From an arts perspective, one of the most surprising and disappointing results of the psychological research was the statistics for pretend play, where the standardized tests did not indicate significant change.⁴ However, the qualitative data contradicted the quantitative, with parents and teachers reporting increased engagement and development in play for most children. One psychologist recorded her experience of being in a room of no toys on her first interview at a family home to being in an environment full of toys at the end of the project. Several parents described imaginative play at home that appeared to reflect the scenic environments (playing with space toys), and a not-altogether-welcome attempt to light campfires using the cooker.

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. ... 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 fifteen minutes for the first time. (Imagining Autism 2014)

After the project ended, observations from teachers indicated ongoing impact, such as participants (drawn from different classes) coming together spontaneously in a snowy January playground to act out the Arctic environment or an 11-year-old boy (with minimal language and challenging behaviour) constructing his own tent (the ‘pod’) in the classroom. These anecdotal reports of the project’s extension into real-world environments raise questions about how pretend play is tested and the potential for measurable change in the course of a ten-week programme of workshops. In discussion, it was speculated that the play-based psychology tests, repeated at short intervals (using identical objects and instructions), may have impacted on children’s performance due to diminished interest in the activities. Hence, they concluded, ‘For some children, improvement was only evident from the parental accounts so capturing home-based behaviours will be important in any future study’ (Beadle-Brown et al. 2017).

Unblinding

Creative tensions between subjectivity and objectivity (also linked to the principle of ‘blinding’) concerned the role of parents as part of the evidential processes. In the pursuit of formal research integrity, parents and teachers as well as psychologists were blinded to the details of the project’s practical approach, knowing only that it was a drama activity. A specially designed parental questionnaire contributed evidence of impact, showing 74 per cent of children with significantly decreased scores (hence improvement) between baseline and post-intervention. However, the value of this data was thrown into stark relief (as well as being potentially compromised) when a parent contacted the school about improvements in her son’s language (e.g. commenting on the car

being 'broken' as it struggles through snow). Her testimony is documented in the project's documentary film (*Imagining Autism* 2014). When the mother asked what the school was doing differently and a teacher made a connection to the project, the mother's request to meet the team and see the methods challenged the evaluative methodology. This incident, coinciding with mounting qualitative evidence of the positive impact of the practical workshops, led to a psychologist PI Dr David Williams (previously blinded) visiting the workshops, a decision that had important implications for the project design and its future direction.

This process of unblinding was to cast new light on the importance of the practical processes, shifting attention to how forms of documentation could be developed that would enable the close analysis and systematic coding of specific interactions between practitioners and children. Suggestions that more cameras should be introduced into the environment and for practitioners to focus on individual children, thereby creating exercises to elicit creative behaviours, were resisted by the arts team as changes that might disrupt the quality of the interactions and relational dynamics, particularly at this late stage in the practical process. It was sometime afterwards, having worked with the footage to respond, analyse and reproduce as different forms of evidence, that we realized our position in what has been variously described as a 'third space' of transdisciplinary research (Sagan 2015), an 'aesthetic third' (Frogett 2008), and as a 'third culture' (Smith 2017). While we understood the difficulties of coding group activities, endorsed the need for rigour and passionately pursued the quest for evidence to identify, articulate and develop the values of the research, we had not taken sufficient account of the complexities of the context, particularly the dynamic relations between the ethical and aesthetic.

The benefit of hindsight has enabled us to re-evaluate the process and to triangulate the interactions between actors (performers and participants as co-producers), action (the work itself as aesthetic object) and reactions (responses from researchers, teachers and parents/carers), creating an iterative feedback loop. The transdisciplinary process was informed by the relational principle that 'agency is located

not in individual actors but in the exchanges between them' (McLeish and Strang 2014).

Moral myopias: Art and instrumentalism

The dialogue between aesthetics and ethics is pervasive in applied theatre and often conceived in terms of dualisms, moving between two primary polarities of art and instrumentalism (White 2015). As Adam Ockelford (2013) has observed in relation to applied music and autism, there is a tendency to conceive of creative engagement in special needs contexts in extra-musical terms, focusing on therapeutic paradigms and the potential of arts activities to promote communication, well-being and social engagement. This myopic vision can lead to musicality being overlooked. In response to this, Ockelford's Sounds of Intent framework is a resource developed for use in special needs contexts as a means of mapping purely musical development in children and young people with learning difficulties (Welch et al. 2009). This tool identifies musical awareness, cognition and expressive capacity. The focus is on auditory engagement with reference to three domains, defined as the reactive (how one responds to sound and music), proactive (how one creates sound and music on his/her own) and interactive (how one creates sound and music in the context of others).

Using this categorization in relation to theatre and the immersive multisensory environments of our drama approach raised some interesting questions around the relations and hierarchies (or not) between the modalities. In some respects, a progression from the reactive via the interactive, leading to the proactive, is a logical development. Thus, for example, a non-verbal child might enter our Space environment and explore the perimeter and scenic features (as so many did) in a *reactive* encounter with the stimuli. The child's curiosity (e.g. picking up a rod puppet) might then lead to a practitioner responding to their cue through eye contact, gesture, vocalization or imitation. The child's response (e.g. moving the puppet in relation to the practitioner), if connected to the

invitation, involves a transition to the *interactive* which practitioners would build upon, scaffolding these responses to create a dialogic exchange. This form of imitative play might then progress from elicited to spontaneous imitation whereby the child begins to improvise a personal choreography through sound or movement. The capacity to engage creatively with others in music-making contexts, particularly in working with autism generally, emerges subsequent to independent individualized expression. A child may respond reactively to sound, progress through imitation to initiating musical activity and then to the complexities of listening and responding to the music of others in group situations.

In drama-based activities involving auditory, visual and physical elements, however, there is a blending of the interactive and proactive so that it is possible to hold more than one in a both/and manner. Footage from the practical processes provided different kinds of data with potential for coding in terms, for example, of attention (the difference between a glance and a look) and the identification and discussion of significant moments. This supplied the basis for a series of case studies, providing data and evidence of practical processes and points of transition. Examples include analysis of Mary's interaction with a woodpecker as her awakening to empathy (Trimingham and Shaughnessy 2016), and the transformation of Eleanor as she moved in a ten-minute sequence from solitary introspection to engage with her peers as Little Foxy, through her adoption of a fur costume and mask (Shaughnessy 2016).⁵ Accessing these materials, I suggest, offers data at least as compelling as statistics on emotion recognition and is a powerful vehicle with which to demonstrate efficacy.

Seeing leaves and forests: Practitioner and participant viewpoints

A further methodological question emerging from the project was the value and status of practitioner and participant perspectives. Gemma Williams, a co-director of the intervention, describes how the project

changed her understanding of autism and her approach to participatory theatre practice:

Before working on imagining autism there were certain things I perceived the diagnosis to be associated with. I knew there was something about autism and a difficulty with communication, emotions and relationships. I remembered a girl at school who had Aspergers. I could clearly picture the way she walked, with a low stopped posture, quick steps and the soft and slightly strange rhythm in her voice. I remembered that she had trouble maintaining eye contact with me and wondered at the similarities and differences between autism and Aspergers. I perceived those with autism as 'different' or in their own world, a world that perhaps I wouldn't understand. I did not know much about the levels of imaginative engagement the children would have.

I tuned into the creative desires of one particular child called Mary. She was mostly non verbal. ... At the start, I felt strongly that she was somewhere else. One character that seemed to captivate her imagination, however, was the fox [who] wore a full head mask and a heavy padded costume. [Foxy was] utterly female, swinging her hips in a low, grounded stance, extending strong but delicate hands and nails to gesture to, or beckon the children to her will. As a practitioner, her presence and physicality allowed me to push the children's physical engagement, getting them moving in embodied play. I think that Mary, being of pre-pubescent age, enjoyed the clear femininity of the fox as she herself was developing feminine behaviours, she copied and cuddled the fox, led her around the space. ... Sometimes the mask would come off, often removed by Mary and placed on her own head, she wanted to be, or embody the fox, she often wore the full padded costume too. As the mask came off, her eye contact with me increased and it got to the stage where the fox costume featured less and less in our games, we found new games, played at being females. (Gemma Williams, personal communication)

In this testimony, the journey described is from a perception of autism as otherness to an empathic cognitive and affective engagement

between practitioner and participant through physical interaction. Williams responds to Mary's emergent sense of her femininity; indeed, she moved into puberty during the project and her difficulties in adjusting to this change (compounded by her autism) were evident at school and in the workshops. Mary's new relationship with her pet cat (reported by her mother to psychologists in interviews before she was aware of the project's methods) is also an example of the development of empathy and its generalization as her new relations with the animal puppets enabled her to make emotional and affectionate connections to her pets at home whom she had previously ignored.

In our pursuit of evidence through *Imagining Autism*, we also sought to engage with participant perspectives, an area where we met considerable methodological and interdisciplinary challenges. In particular we incorporated drawing and mark-making into our environments in an effort to gather as much data as possible from participants, particularly as many were non-verbal. This did not become a formal feature of the research design as it emerged in the course of the project, and there were concerns from psychologists about the tools we would use to analyse the drawings and the theoretical basis for their interpretation. They also advised that the drawings could not be reliable data for subjective experience as they may not necessarily reflect a child's self-awareness.

Nonetheless, we continued to incorporate drawing or art-making opportunities, using materials appropriate to the environments (such as white chalk in the Arctic). The pictures were subsequently used as occasional display materials, or as illustrations at conferences, but remained largely invisible as evidence. Yet this archive reveals something about the participant experience and we continue to speculate on what the drawings might tell us and their potential value to future research, as they appear to give some indication of how participants engaged with the work. All the drawings are accompanied by annotations made by the practitioners about the commentary the children made as they produced them. These give insight into the intention and thought processes. What were drawn consistently were self-representations of the participating children in relation to aspects of the pretence frameworks (e.g. fictional

characters and props). Mary's Forest drawings, for example, focus on her relationship with the practitioner (Melissa Trimmingham, the co-investigator leading the practical methods) she was working with and who is named in her pictures.

A sequence of pictures by Mary begins with different elements drawn individually. The first picture shows a pumpkin-shaped face (orange circle with vertical lines, eyes and mouth) labelled Melissa and a witch's hat identified as Mary. In the second picture, a stick figure of a smiling witch, or scarecrow, is drawn with brown lines outlining the body and orange appearing to represent the costume. The brown hat and face are labelled Melissa, and the orange body or costume is labelled Mary. One possibility is that this is Mary showing herself taking on the costume or role of the witch. The third picture is labelled 'All Mary', and shows the witch complete with hat and dress. The pictures blend the real and imagined. Mary associated the Forest environment with Halloween (due to the workshop being in October), and the autumnal colours and textures of the Forest, including leaves on the floor. The pumpkin and witch characters, however, are her invention. We see Mary working out her identity in relation to Melissa (as other), and then imagining herself as a character in an image she creates associatively. Her drawings show a progression from the assembly of different parts, through the blending of Melissa/costume/Mary, to the Mary-witch. By bringing associative elements into their pictures, imaginatively projecting their lived experiences into their drawings, Mary and other participants are creating versions of Paul Ricoeur's 'configurational acts' (1991: 106).

These refer to the non-chronological production of meaning from past, present and future events. It is described as a 'grasping together', an act of 'eliciting a pattern from a succession'. In her discussion of the body as narrative, Gail Weiss (2003) suggests that 'the configurational act, as a spontaneous organizational strategy, can itself be understood as a Gestalt, or figure/ground organization' that produces what Ricoeur calls a 'constellation of meaning' (29). Weiss draws attention to the role of the body in 'the organization and production of an integrated sense of self'. Mary's drawings offer insights into this process through

an activity that integrates her physical experience (and memory) of embodying an imagined other through the act of performance with her emerging sense of self. Weiss conceives of 'a tacit organisation to our narratives that is due not to cognition or emotion but to the body itself as the ultimate ground for all narrative construction' (2003: 32), so that imagination is an embodied activity.

Conclusion: Messages in bottles and aes/ethics

In the Underwater environment at School 2, Amy's response to our drawing request was to write a note, rather than producing a drawing: 'Who are you and what's you're [*sic*] name,' she wrote, explaining that she was 'writing to the person who had left the message in a bottle'. The bottle had been a loose item, left to be discovered by one of this highly verbal group who showed an interest in constructing elaborate scenarios, introducing new characters (such as on one occasion a dog in space), and who we anticipated would respond to this trigger. Amy's discovery of the bottle led to a group search to locate a hidden character on our imaginary island. Amy's diagnosis of autism means she is considered to have difficulties in social imagination, in understanding and engaging with the perspectives of others. Her creative response to the stimuli is evidence of her capacity for imaginative engagement; she found the original message in the bottle, knew it was not real in the context of the theatre framework, but understood the rules of the drama game in which she was a player. As a co-producer, she contributed to the development of the devised narrative through interactive and proactive strategies. She imitated and scaffolded our action, extending it by writing to an imaginary character of her own invention and inviting a response. Her action refers to the past of the workshop and anticipates a possible follow-on from whoever receives the bottle. In so doing, I suggest, she was working self-reflexively in role, knowing it was both real (a game to be played in the moment) and not real: she was pretending to pretend. Amy was also showing her capacity to work between past, present and

future as structures for new meaning for herself and imagined others (both the fictional character to whom she writes and the real of the practitioner or researcher who will read the note).

What is missing from this analysis, however, is acknowledgement of Amy's creativity as an artist. The message in the bottle is an example both of social imagination as psychologists understand it and of the creative imagination we value in art. In evaluating this work, we are seeking to hold both ethical and aesthetic considerations in mind (and body, as affective responses and affect theory inform this account). Our significant moments will almost invariably involve ethical and aesthetic dimensions in this both/and configuration. A further feature conjoining these elements is the relational context in which these moments are situated and/or the act of witnessing by the audience for the work. This creates the aesthetic third, the feedback loop wherein thinking and feeling coalesce and we become aware of our positions or perceptions shifting as we are affected by the artefact or action we are observing or interacting with. The significance of this aesthetic encounter was brought into focus for me by Andy Hurst, a multimedia performance practitioner and teacher who was visiting the project to advise on how we might enhance the immersive nature of the environments through projection and digital media. We were watching a small group of children with autism interacting in a portable Arctic environment, a makeshift structure created as a one-off training event using materials from our main environment (paper snowflakes, dustsheets blowing from cold-air fans, reflective foil as water and interactive snowmen). He watched for ten minutes, absorbing the scene, then turned to me and said, 'It's a film ... you don't need anything else. Watching this reminds me of Robert Wilson; they are artists making work.' These observations based on an aesthetic encounter are important to the creative and critical tensions we continue to negotiate and balance in this dialogic third space between art and science.