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idea journal

co-constructing body-environments

vol. 17, no. 02

2020

the journal of IDEA: the Interior design +
interior architecture educators' association



vol.17, no.02
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body-environments



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interior architecture educators' association

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IDEA (Interior Design/Interior Architecture Educators' Association) was formed in 1996 for the advancement and advocacy of education by encouraging and supporting excellence in interior design/interior architecture education and research within Australasia.

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The objectives of IDEA are:

1. Objects

3.1 The general object of IDEA is the advancement of education by:

- (a) encouraging and supporting excellence in interior design/interior architecture/spatial design education and research globally and with specific focus on Oceania; and
- (b) being an authority on, and advocate for, interior design/interior architecture/spatial design education and research.

3.2 The specific objects of IDEA are:

- (a) to be an advocate for undergraduate and postgraduate programs at a minimum of AQF7 or equivalent education in interior design/interior architecture/spatial design;
- (b) to support the rich diversity of individual programs within the higher education sector;
- (c) to create collaboration between programs in the higher education sector;
- (d) to foster an attitude of lifelong learning;
- (e) to encourage staff and student exchange between programs;
- (f) to provide recognition for excellence in the advancement of interior design/interior architecture/spatial design education; and
- (g) to foster, publish and disseminate peer reviewed interior design/interior architecture/spatial design research.

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**co-constructing body-environments:
provocation**

Presenters at *Body of Knowledge: Art and Embodied Cognition Conference (BoK2019)* hosted by Deakin University, Melbourne, June 2019) are invited to submit contributions to a special issue of idea journal "Co-Constructing Body-Environments" to be published in December 2020. The aim of the special issue is to extend the current discussions of art as a process of social cognition and to address the gap between descriptions of embodied cognition and the co-construction of lived experience.

We ask for papers, developed from the presentations delivered at the conference, that focus on interdisciplinary connections and on findings arising from intersections across research practices that involve art and theories of cognition. In particular, papers should emphasize how spatial art and design research approaches have enabled the articulation of a complex understanding of environments, spaces and experiences. This could involve the spatial distribution of cultural, organisational and conceptual structures and relationships, as well as the surrounding design features.

Contributions may address the questions raised at the conference and explore:

- + How do art and spatial practices increase the potential for knowledge transfer and celebrate diverse forms of embodied expertise?
- + How the examination of cultures of practice, Indigenous knowledges and cultural practices offer perspectives on inclusion, diversity, neurodiversity, disability and social justice issues?
- + How the art and spatial practices may contribute to research perspectives from contemporary cognitive neuroscience and the philosophy of mind?
- + The dynamic between an organism and its surroundings for example: How does art and design shift the way knowledge and thinking processes are acquired, extended and distributed?
- + How art and design practices demonstrate the ways different forms of acquiring and producing knowledge intersect?

These and other initial provocations for the conference can be found on the conference web-site: <https://blogs.deakin.edu.au/bok2019/cfp/>.

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introduction: unknowingly, a threshold-crossing movement

Julianna Preston

Executive Editor

idea journal

It is in this special issue that the editorial board holds true to our promise to expand the horizons and readership of *idea journal* while reaching out to associated and adjacent art, design and performance practices and drawing connections to seemingly distant disciplines. The articles in this issue have provenance in a 2019 conference event, Bodies of Knowledge (BOK), which was guided by a similar interdisciplinary ethos. With an emphasis on cultures of practice and communities of practitioners that offer perspectives on inclusion, diversity/neurodiversity and disability, this conference, and this subsequent journal issue, aim to increase knowledge transfer between diverse forms of embodied expertise, in particular, between neuroscience and enactive theories of cognition.

This brief description suggests that there are shared issues, subjects and activities that have the potential of generating new understanding in cross-, inter- and trans-disciplinary affiliations and collaborations. My experience in these modes of inquiry points to the importance of identifying what is shared and what is not amongst vocabulary, concepts, pedagogies and methods. Holding these confluences and diverges without resorting to strict definition, competition or judgement of right and wrong often affords greater understanding and empathy amongst individuals to shape a collective that is diverse in its outlooks, and hopefully, curious as to what it generates together because of that diversity.

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The breadth of the knowledge bases represented within this issue necessitated that the peer reviewer list expanded once again like the previous issue. It was in the process of identifying reviewers with appropriate expertise that the various synapses between scholarly and artistic practices became evident. It is these synapses that shape sturdy bridges between the journal's existing readership, which is predominantly academics and students in interior design, interior architecture, spatial design and architecture, and the wide range of independent scholars and practitioners, academics, and students attracted to BOK's thematic call for papers, performative lectures and exhibitions. At the risk of being reductive to the complexity and nuances in the research to follow, I suggest that the following terms and concerns are central to this issue, aptly inferred by its title, 'Co-Constructing Body-Environments': spatiality; subjectivity; phenomenology; processual and procedural practice; artistic research; critical reflection; body: experience. All of these are frequent to research and practice specific to interiors. In this issue, however, we find how these terms and concerns are situated and employed in other fields, in other ways and for other purposes.

This is healthy exercise. To stretch one's reach, literally and metaphorically is to travel the distance between the me and the you, to be willingly open to what might eventuate. Imagine shaking the hand of a stranger—a somatic experience known to register peaceful intent, respect, courage, warmth, pressure, humour, nervous energy, and so much more. This threshold-crossing movement is embodied and spatial; it draws on a multitude of small yet complex communication sparks well before verbal impulses ensue. This significant bodily gesture sets the tone for what might or could happen. Based on my understanding of the research presented in 'Co-Constructing Body-Environments,' I propose that this is a procedure in the Gins and Arakawa sense that integrates theory and practice as a hypothesis for 'questioning all possible ways to observe the body-environment in order to transform it.'⁰¹ I call this as *unknowingly*—a process that takes the risk of not knowing, not being able to predict or predetermine, something akin to the spectrum of 'throwing caution to the wind' and 'sailing close to

the wind'. My use of the word 'unknowingly' embraces intuition where direct access to unconscious knowledge and pattern-recognition, unconscious cognition, inner sensing and insight have the ability to understand something without any need for conscious reasoning. Instinct. The word *unknowingly* also affords me to invoke the 'unknowing' element of this interaction—to not know, to not be aware of, to not have all the information (as if that was possible)—an acknowledgement of human humility. I borrow and adapt this facet of unknowingly from twentieth-century British writer Alan Watts:

This I don't know, is the same thing as, I love. I let go. I don't try to force or control. It's the same thing as humility. If you think that you understand Brahman, you do not understand. And you have yet to be instructed further. If you know that you do not understand, then you truly understand.⁰²

Unknowingly also allows me to reference 'un' as a tactic of learning that suspends the engrained additive model of learning. Though I could refer to many other scholarly sources to fuel this concept, here I am indebted to Canadian author Scott H. Young's pithy advice on how to un-learn:

This is the view that what we think we know about the world is a veneer of sense-making atop a much deeper strangeness. The things we think we know, we often don't. The ideas, philosophies and truths that guide our lives may be convenient approximations, but often the more accurate picture is a lot stranger and more interesting.⁰³

In his encouragement to unlearn—dive into strangeness, sacrifice certainty, boldly expose oneself to randomness, mental discomfort, instability, to radically rethink that place/ your place/ our place, suspend aversions to mystery—Young's examples from science remind us that:

Subatomic particles aren't billiard balls, but strange, complex-valued wavefunctions. Bodies aren't vital fluids and animating impulses, but trillions of cells, each more complex than any machine humans have invented. Minds aren't unified loci of consciousness, but the process of countless synapses firing in incredible patterns.⁰⁴

In like manner to the *BOK2019* conference which was staged as a temporally infused knowledge-transfer event across several days, venues, geographies and disciplines, I too, ingested the materials submitted for this issue in this spirit of unknowingly. The process was creative, critical, intuitive, generative and reflective—all those buzz words of contemporary research—yet charged with substantial respect and curiosity for whatever unfolded, even if it went against the grain of what I had learned previously. For artists, designers, architects, musicians, and performers reading this journal issue, especially academics and students, this territory of inquiry may feel familiar to the creative experience and the increasing demands (and desires) to account for how one knows what one knows in the institutional setting. ‘Explain yourself,’ as the review or assessment criteria often states. If you are faced having to annotate your creative practice or to critically reflect on aspects that are so embedded in your making that you are unaware of them, I encourage you to look amongst the pages of this journal issue for examples of how others have grappled with that task such that the process is a space of coming to unknow and know, unknowingly.

Figure 01:

Meeting the horizon; A still image from *Shore Variations*, a 2018 film by Claudia Kappenberg that reimagines *Waning*, a 2016 live art performance by Julieanna Preston. <https://vimeo.com/user11308386>.

There are a few people I would like to acknowledge before you read further. First, huge gratitude to the generosity of the peer reviewers, for the time and creative energy of guest editors Jondi Keane, Rea Dennis and Meghan Kelly (who have made the process so enjoyable and professional), for the expertise of the journal's copy editor Christina Houen and Graphic Designer Jo Bailey, and to AADR for helping to expand the journal's horizons.

Okay, readers, shake hands, consider yourself introduced, welcome into the *idea journal* house, and let's share a very scrumptious meal.

acknowledgements

I am forever grateful for what life in Aotearoa/ New Zealand brings. With roots stretching across the oceans to North America, Sweden, Wales and Croatia, I make my home between Kāpiti Island and the Tararua Ranges, and in Te Whanganui-A-Tara/ Wellington. I acknowledge the privilege that comes with being educated, employed, female and Pākehā, and the prejudices and injustices that colonialism has and continues to weigh on this land and its indigenous people. I am committed to on-going learning and practicing of Kaupapa Māori.

notes

- 01 Jondi Keane, 'An Arakawa and Gins Experimental Teaching Space; A Feasibility Study,' *INFLeXions* 6 (2012), accessed 29 October 2020, http://www.inflexions.org/n6_keane.html.
- 02 Alan Watts, *Creating Who You Are* (Video) (n.d.), accessed 29 October 2020, <https://vimeo.com/76888920>.
- 03 Scott H. Young, 'The Art of Unlearning' (2018), accessed 29 October 2020, <https://www.scotthyoung.com/blog/2018/04/12/the-art-of-unlearning/>.
- 04 Young, 'The Art of Unlearning.'

'stim your heart out' and 'syndrome rebel' (performance artworks, autism advocacy and mental health)

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abstract

'Stim Your Heart Out' is a set of concepts and beliefs that advocate the benefits of the autistic culture of 'stimming', a repetitive physical action that provides enjoyment, comfort and contributes towards self-regulation of emotions. Facilitating the exploration of contemporary movement in the context of stimming and self-regulation, workshops generated a series of movement scores, culminating in a patented choreographic system of stimming performances documented at the www.stimyourheartout.com website and associated film.

'Syndrome Rebel' utilises this new choreographic system, where a performative movement score was created. A new stimming symbology/language was then developed and embroidered around the edge of a circular blanket, to record the movement score in this new symbology. The artist then interacted with these symbols within a live integrated movement score stimming performance. Continuing the conversations of Civil Rights and Feminism, the work uses textiles, language and performance to challenge the use of deficit language by the medical academic fraternity, and to protest against social behavioural norms, and the stigma that medical and educational practitioners and society associate with autistic behaviours, due to their medicalised perspective of 'cure.' These works advocate for autistic people to be able to celebrate and practise their autistic culture, while sharing the self-awareness of our sensory perception and neuroperspective with the rest of society.

The project and performance address the prevalence of mental health conditions among autistic people, raise the discussion of art as a process of social cognition, and speak to the gap between descriptions of embodied cognition and the co-construction of lived experience. 'Stim Your Heart Out' project and 'Syndrome Rebel' performance make connections across my lived-experience and research practices within the arts and sciences.

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keywords:

autism, consultant, stimming, self-regulation, lived-experience, neurodiversity, deficit language, meltdowns

performance artworks and theory

This article discusses two of my artworks: 'Stim Your Heart Out,' which is a developmental project that workshopped stimming movement scores into a proposed performance art form, whilst advocating for autistic cultural space; and 'Syndrome Rebel,' the associated initial project extension movement score performance artwork, which developed an associated symbolic language for documenting both the movement score and the artist's interactions with it during the performance.

These artworks are introduced as manifestations of my lived experience and the direct connection of my art practice to my identity as an autistic woman, overlaid on the environments in which I live, work and breathe. They raise aspects of mental health, autism advocacy and art as a process of social cognition, addressing the gap between descriptions of embodied cognition and the co-construction of lived experience.

lived experience research

The 'Stim Your Heart Out'⁰¹ project and 'Syndrome Rebel'⁰² performance artwork draw upon the breadth of my lived experience, extending from my attendance in the K-12 education system. Flipping between mainstream and disability schooling, I eventually dropped out of school after being expelled. Years later, I found acceptance within the art school environment of my university, particularly in the Master of Art program, where my supervisor helped me feel safe by never judging my meltdowns as deficit.

This lived experience includes exposure to childhood medical practices, where I received an incorrect ADHD diagnosis at seven years and was subsequently incorrectly prescribed Ritalin, to finally being diagnosed with Asperger's Syndrome aged eleven years (with some learning difficulty add-ons such as dyslexia). This diagnosis has been redefined as Autism Spectrum Disorder (ASD) in my adult years, and I now consider myself part of the neurodiverse community.

My lived experience also includes my professional work as an autism consultant for Amaze (Ex Autism Victoria), Project Officer with Annecto Disability Service, attendance at Autism Conferences such as APAC17, and participation in a variety of autism PhD research programs at Deakin University, Olga Tennison Autism Research Centre (OTARC) at Latrobe University, and Cooperative Research Centre for Living with Autism (Autism CRC) at Queensland University, as I searched for the latest thoughts and knowledge within the academic, advocacy, and disability care communities, to compare with my own lived experience of autism.

This is where I met Professor Peter Enticott⁰³⁰⁴ within the Deakin University School of Psychology research programs I was participating in. Peter has been a wonderful sounding board for my lived-experience ideas on autism and how the academic world looks at those specific elements, particularly as I began to explore and document my own research. Peter was also kind enough to be the mental health stakeholder for my 'Stim Your Heart Out' Project and provided the

introduction for my *BoK2019* 'Syndrome Rebel' presentation,⁰⁵ performance,⁰⁶ and Q&A.⁰⁷ In finding my own lived-experience conclusions on aspects of mental health and how they related to stimming and self-regulation, whilst having no formal qualifications in psychology, I thought it was important for my projects' credibility to find a trusted and experienced ally in Professor Peter Enticott; he had an interest and concern in this area, and was willing to become a stakeholder partner on the project, and add his expertise when and if required.

My personal and family relationships have also been of considerable importance to my lived-experience, particularly in the way my dad describes how I live on a 'knife edge,' constantly flipping from one side, 'passing' and negotiating the non-autistic 'mainstream' world, to the other, being wonderfully autistic. In general, I have spent most of my life not quite fitting into either mainstream or disability-designed systems. This is why I fight for less segregation, because I believe that in order for systems to be accessible to all, they need to be written by all. Due to my lived experience as an autistic person, I have critical insight into what it means to be autistic and why certain behaviours manifest. For example, understanding the function of the behaviour. This is a step-by-step structure I have come to understand as follows: I have a behaviour, I question the behaviour, I work out the function of the behaviour. If its function is to help cope in an environment because of sensory sensitivities, I attempt to advocate for the environment to accommodate me. If that's not an option or the behaviour is for a different

reason (e.g. such as emotion regulation, or the inability to advocate for myself, or a repetitive thought pattern that doesn't feel good), I will hone in on my individual sensory profile, for the senses I'm under-responsive to, and create a behaviour with a positive sensory feedback loop, whilst aiming for the behaviour to be safe for me and safe for others.

Because the behaviour is coming from me and I am experiencing the pain, I have insight into the function of my behaviours and my unique environmental, emotional, and social experience. 'Stim Your Heart Out' and 'Syndrome Rebel' are about creating safe spaces for the broader understanding and acceptance of these autistic behaviours that can also be applied in a universal design sense for all minds and bodies.

'stim your heart out' advocacy project details

'Stim Your Heart Out' is a set of concepts and beliefs that advocate the benefits of the autistic culture of stimming, a repetitive physical action that provides enjoyment, comfort, and contributes towards self-regulation of emotions. As the founder of 'Stim Your Heart Out,' the idea came from a growing need to advocate for my autistic self, while learning to unmask.

so everyone can learn how to self-regulate in a way that is safe for them and others);

04. Help non-autistics to learn from the autistic experts in self-regulation (because non-autistic society has suppressed self-regulation, resulting in outbursts in unsafe ways, e.g. domestic violence, road rage, depression, suicide, self-harm etc.); and,
05. Help mainstream society realise they are so invested in everyone being happy that they are leaving less space for people to express alternative emotions.

Figure 01:
'Stim Your Heart Out' Film Trailer
Title Page, 2018. Image provided by
the Artist/Founder, Prue Stevenson.

Beliefs

01. Stimming is the innate behaviour, inborn in us all, that links everybody together (we all, for example, click pens, bounce our legs and pace up and down under stress); and,
02. Understanding the value of stimming and 'self-regulation' can create an inclusive understanding between everyone in society.

Concepts

01. Reinforce autistic culture (e.g. establish the language of stim and stimming so as to empower the autism community);
02. Integrate autistic culture into mainstream society (so autistic people can be themselves and feel safe with stimming or 'meltdowns' in public if they want or need);
03. Re-prioritise the mainstream education system, with self-regulation to be integrated into mainstream schools in the same manner as sex education (i.e. stimming should not be a taboo subject,

Workshops

The project workshops facilitated the exploration of contemporary movement in the context of stimming and self-regulation. The workshops generated a series of movement scores, culminating in a patented choreographic system of stimming performances documented at the 'Stim Your heart Out' Project website and associated film.

Figure 02:
'Stim Your Heart Out' Workshop,
Melbourne, 2018. Image by the
Artist/Founder Prue Stevenson.

'syndrome rebel' movement score performance details

'Syndrome Rebel' utilises this new 'Stim Your Heart Out' choreographic system to develop a creative performative movement score. A new stimming symbology/language was then developed and embroidered around the edge of a circular blanket, to record the movement score in this new symbology. The artist then interacted with these symbols within the work, in a live, integrated movement score stimming performance.

This new performance artwork creates a safe space for the broader understanding and acceptance of these autistic behaviours that can also be applied in a universal design sense for all minds and bodies. The work continues the conversations of civil rights and feminism, using textiles, language and performance to challenge the use of deficit language by the medical academic fraternity, aiming to protest against social behavioural norms, and the stigma that medical and educational practitioners and society associate with autistic behaviours, due to their

Figure 03:

'Syndrome Rebel' Performance Artwork (sitting & stimming), Masters ADR Examination, RMIT, 2019. Film still of performance courtesy of professional art documenter Allyn Laing from Docutive (www.docutive.com).

Figure 04:

Spinning and stimming during 'Syndrome Rebel' Performance Artwork, Masters ADR Examination, RMIT, 2019. Film still of performance courtesy of professional art documenter Allyn Laing from Docutive (www.docutive.com).

medicalised perspective of cure. It advocates for autistic people to be able to celebrate and practise their autistic culture, while sharing the self-awareness of our sensory perception and neuropsychology with the rest of society.

behavioural interventions; and, being taught to suppress or mask my stimming or self-regulating autistic behaviours (i.e. by 'passing' as non-autistic, to try and fit into the expected 'mainstream' societal norms). Key areas of research are outlined below.

The initial sections of academic research on Disability/Deficit Language, Children's Autistic Play, Conferences, and Reclaiming Stimming as Therapy offer the reader some understanding of the justification for reclaiming stimming as a natural autistic culture to be expressed as required in mainstream scenarios.

The later sections of academic research on Autistic Experts, Disability Arts, and Defining Empathy combine to show an emphasis on my artworks and disability arts in general, and the way in which this genre postulates art informing theory.

Disability/deficit language

Where semiotics means the study of signs and symbols and their use or interpretation, and praxis means it is accepted practice or custom, Nolan and McBride state the following in their Abstract (for their associated article):

Within the medicalized semiotic domain of autism as disease, autistic sensory experience is classified as a sensory integration 'disorder.' The senses, sensory perception and integration are, for autistics, the authority and the warrant by which disablement and psychiatric intervention are rationalized as the purview of medical

Figure 05:
'Syndrome Rebel'- detail of the
hand-embroidered woollen blanket.
Image by the Artist Prue Stevenson,
2019.

academic research

My academic research found me reflecting on: my lived-experience of education from early childhood years of sensory play, researching various aspects of childhood innocence and interactive stimming in children's sensory play (i.e. before being influenced by societal behavioural norms); through the primary school years, getting bullied a lot (with confused social skills capabilities); receiving mis-managed

and institutional power/knowledge. This positioning reinforces and produces a normative sensory ideal. This semiosis of medicalized discursive practices reduces the disabled person to an essentialized biological body. It is also a semiotic process that discursively constructs the autistic in a deficit-driven language of disease rather than difference. Recognizing the discursive and semiotic nature of disablement, autistic self-advocates (also self-identified as 'neurodiverse') coined the term 'neurotypical' to define non-autistic subjectivity, sensory orientations and social norms on their own terms. As with deaf culture, the neurodiversity movement defines itself as a social and cultural identity rather than impairment. In this chapter, the authors, who are both autistic, explore the possibilities for new literacies of neurodiverse expression and epistemologies that are more self-reflexive about the nature of the semiotics to configure and periodize a sensory imaginary to engage the nullified and revolutionary experience of feeling, sensing and understanding beyond the neurotypical.⁰⁸

The use of deficit language in the disability sector means that children with disabilities are set up for failure right from the start, when in fact, there are many things that they can do well that could start them on a positive pathway.

Children's autistic play

In his article on 'vivid rememberings' and 'interactive stimming,' Conn discusses autistic perceptions, concluding: 'Autistic autobiographies give rise to the notion that a distinctive autistic play culture exists, one that is sensory based rather than socially mediated and concerns exploration of the world as it is autistically perceived and experienced.'⁰⁹ He then goes on to discuss the value of autistic perceptions, concluding: 'Play is of intrinsic value to the individual, providing important leisure time and a space where they can be themselves';¹⁰ 'Lack of recognition of the richness of sensory and physical play and of the enjoyment that it provides to children, for example, means that some children are stopped from playing and not given access to suitable play materials.'¹¹ Conn also discusses the impacts of setting up barriers to these autistic perceptions for the individual, concluding:

Barriers to children playing in ways that provide them with the most happiness and satisfaction has implications for the development of their health and well-being and could be seen as contributing to the construction of negative identities and marginalised roles, and to the stress of 'acting normal.'¹²

Conferences

It appeared evident to me that a conference that was organised by medical and educational academics, who still used deficit language and allowed the stigmas of mainstream society to influence them, did

not cater well enough for the lived experience of autistic people. Nor was the conference accessible for the target minority group, due to the costs involved, particularly when you compare it to the employment and mental health statistics for the autism community. This evidence is born out in the fact that the APAC17 Program¹³ did not use the terms 'stimming' or 'self-regulation' once in their whole four day/eleven parallel streams conference, nor did they accept a presentation on the 'Stim Your Heart Out' Project, stating that it did not align with the theme of the conference. In comparison, it was the arts community, through the Lesley Hall Art Grant facilitated by Arts Access Victoria (AAV),¹⁴ who funded the making of Phase 1 of the 'Stim Your Heart Out' project.

Reclaiming stimming as therapy

Kapp, in 'People Should be Allowed to Do What They Like: Autistic Adults' Views and Experiences of Stimming,' states:

Supported by a growing body of scientific research, autistic adults argue that these behaviours may serve as useful coping mechanisms, yet little research has examined stimming from the perspective of autistic adults; ... Research suggests that non-autistic people often misunderstand the behaviour of autistic people, likely contributing to autistic people's socio-communicative challenges.¹⁵

Kapp also states in his news article, 'Stimming, Therapeutic for Autistic People, Deserves Acceptance,' that: 'The neurodiversity

movement, which celebrates autism both as a way of being and a disability to accept and support, has embraced stimming'; he uses my 'Stim Your Heart Out' Project as a supportive resource to his academic claims.¹⁶

Autistic experts

Gillespie-Lynch, in 'Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts,' states:

Traditional expert knowledge of autism derives from observations by professionals who often lack the lived experience of being autistic, whose understanding and acceptance of autism might increase by listening to autistic people ... Findings suggest that autistic adults should be considered autism experts and involved as partners in autism research.¹⁷

Milton, in 'Autistic Expertise: A Critical Reflection on the Production of Knowledge in Autism Studies,' states:

The field of autism studies is a highly disputed territory within which competing contradictory discourses abound. In this field, it is the voices and claims of autistic people regarding their own expertise in knowledge production concerning autism that is most recent in the debate, and traditionally the least attended to.¹⁸

'Stim Your Heart Out' and 'Syndrome Rebel' aim to create safe spaces for the autistic experts to research their own lived-experience

and communicate their understandings to the broader society through shared experiences of embodied cognition.

Disability arts

Sarah Houbolt states that 'a lot needs to be done' before society can embrace disabled artists; she is concerned with 'unravel[ing] misconceptions [the audience] might have when they see her walk on stage.'¹⁹ When I stim in a gallery setting, it is about unravelling these same misconceptions. In contrast to the public sphere, galleries present an invitation for people to observe work with interest and curiosity without the overlay of social ideologies. In this way, 'Syndrome Rebel' creates an invitation for society to watch and get familiar and comfortable with autistic stimming.

Defining empathy

Fletcher-Watson, in 'Autism and Empathy: What are the Real Links?' states,

There is no standard, agreed-upon definition of empathy used in research. One dictionary definition is 'the ability to understand and share the feelings of another' with synonyms including 'affinity with, rapport with, sympathy with, understanding of, sensitivity towards, sensibility to, identification with, awareness of, fellowship with, fellow feeling for, like-mindedness, togetherness, closeness to.'²⁰

In the context of this long and varied list of synonyms, it is easy to see why having the capacity for empathy is often seen as a

defining characteristic of being human, and why empathy is such a hard concept to pin down, and consequently to test.

Further, society has a common misunderstanding that autistic people are lacking empathy, that they tend to display their feelings differently or appear to be cold and distant when they are feeling overwhelmed, when in fact they could be experiencing the pain of hyper-empathy. Fletcher-Watson states, 'How can we do better? A first step is certainly to take into account what autistic people tell us about their experience of empathy. Autistic people have described that they experience "... hyperarousal of the empathic system."

'Syndrome Rebel' cuts through these difficulties of empathy and understanding by presenting a creative art form that can be enjoyed through a shared experience of embodied cognition.

mental health

Mental health lived experience

Reflecting on my lived-experience, I spent most of my energy as a child 'passing' as non-autistic, which resulted in me gaining limited access to the K-12 education system. Now that I am an adult, I still have to spend most of my energy advocating for my access needs. Both situations cause detrimental effects to my mental health. These mental health issues are evidenced in the Amaze 'Autism and Mental Health' web article statistics.²¹ At APAC17, a presentation by Dr Samuel Odom, 'Are school-based interventions the 'best hope' for children and youth with autism spectrum

disorder?' caught my attention, particularly his 'Matrix of Evidence Based Practices'. This matrix had a column for Mental Health efficiency benefits and outcomes, which was almost empty, flagging that more research should be done in that area. I feel that 'Stim Your Heart Out' and 'Syndrome Rebel' fit exactly into that empty Mental Health column, and hope that greater exposure of the projects will work towards: making stimming part of mainstream society's language; and creating an understanding of the mental health benefits of self-regulation for all types of minds and bodies, by having mainstream society learn from the autistic community's experts in stimming and self-regulation. 'Stim Your Heart Out' was subsequently invited to present at the Aspect Autism in Education Conference (AIE2018),²² where my slide comments on Dr Odom's flagging of the current mental health status, mentioned above, are viewable at Section 2.7.1 of the presentation. Nolan and McBride suggest that stimming may actually benefit non-autistics who, similarly, are 'conditioned to resist such physical utterance.'²³ I hope that those who experience this work will be prompted to reflect on their own experience of stimming and allow themselves to begin self-regulating on the basis of improving mental health.

In trying to dissuade people from conditioning autistics to suppress urges to stim, this project illustrates more 'inclusive visions of sociality' by 'disrupting narratives of autism as deficit or disease.'²⁴ I feel I can influence people to adjust their priorities from social conformity to social acceptance of a valid lived experience. Until very recently most people of the autistic

community have felt incompatible in the wider society. A history of segregation through institutions, eugenics, segregated schooling systems, and misdiagnosis, has led to a disconnection, and by design, society does not accommodate the needs of autistic people.

Deficit language, diagnosis and support: Impact on mental health

In my AMAZE autism consulting role, I often commence by talking about the medical model versus social model of disability, and how I translate medical deficit language into empowering lived experience language. I explain how the diagnostic criteria is designed currently in the DSM-5²⁵ with level 1 (some support), formally known as Asperger Syndrome, level 2 (high support) and level 3 (very high support). Currently autistic people diagnosed with level 1 autism aren't able to access support such as the National Disability Insurance Scheme (NDIS).²⁶ I believe this is the demographic of autism which is most likely to use all their capacity to mask. Some autistic people can have a rigid way of thinking, which can impede the way they navigate systems such as government support. If you asked me when I was sixteen years old to identify with medical language I would have said 'no, I'm not disordered,' 'I'm not impaired,' 'I don't have a disability.' After a lot of coaching from my father, I gained an understanding of my individual access and support needs, which is why I know I need to use deficit language if I want to gain the support I need to achieve my goals. I also know it is not sustainable for me to describe myself with that same language. This is why

I need two languages. Without NDIS support, I believe autistic people diagnosed with Level 1 have a higher chance of requiring serious mental health support later in life. In my lived experience of masking and having an original diagnosis of Asperger Syndrome, I didn't practice consistent self-regulation, I couldn't advocate for myself to get opportunities and access support without disclosing I am autistic, and I used all my capacity to mask my autism instead of it going towards my education in areas other than how to be a non-autistic. All my masking manifested in behaviours of concern, particularly banging my head on objects such as walls and tables to get lots of feedback from my vestibular sense.

Autism research history: Impact on mental health

The way that autism is perceived is closely connected with its history in medical research. When Hans Asperger's research was translated into English, autistic boys who are highly knowledgeable in one area and lack social capacity were described as having level 1 autism, previously Asperger Syndrome.²⁷ When Asperger's research was related to Leo Kanner's research, looking at autistic boys who have repetitive movements, are non-verbal and are seemingly unaware of their environment and the people around them, this became known as level 3 autism.²⁸ When these two pieces of research came together, this is where the concept of the autism spectrum and of high and low functioning autism came from. When the spectrum was described to me as a young person, instead of it being explained as level 1 autism at one end and level 3 autism at the other end of a

spectrum, it was described to me as autism at one end and non-autistic at the other end. The closer I was to autism the more I would be in trouble, get punished, or miss out on opportunities. The closer I was to non-autistic, the more praise and opportunities I would get; this is how a lot of autistic people are coached out of their natural autistic way of being. Of course, it is never going to be sustainable to keep up appearances all the time, and eventually, my brain gets tired and overworked and shuts down, causing a meltdown. This is when all the unfiltered autistic behaviours come out and I, until very recently, would get flooded with feelings of guilt and shame and think I was a monster. All because I was being deprived from self-regulating because it is highly stigmatised.

The autism spectrum: Linear versus holistic and fluctuating

When I train people in autism, I explain to them both the old/current linear way of perceiving the autism spectrum, and the way that autistic advocates like myself think about it. I use the analogy of a colour wheel where each colour represents a skill (e.g. executive functioning, sensory, social communication etc.) and the gradient of each colour represents levels 1, 2, and 3. Where the individual sits fluctuates. The individual could be level 2 in sensory and level 1 in social communication skills. Then when the individual gets tired, they might be level 3 in sensory and level 2 in social communication skills.

Advocating versus masking: Impact on mental health

I would rather use my brain's capacity advocating for my access needs than mask my autism. By advocating, I am able to make change and mould environments to fit me. When they embody universal design, I don't need to work so hard on advocacy and instead get to use my capacity for the actual reason I am there. When I mask my autism, it's not sustainable. I am using all my brain's capacity to make people around me more comfortable, then I get tired and start behaving autistic, and people aren't used to that, and I lose opportunities. When I mask my autism, I haven't got enough opportunities to self-regulate and that affects my mental health and I have more behaviours of concern. It takes a lot of confidence to behave autistic when you have learnt to be hyperaware of your behaviours and how they make people around you uncomfortable or think less of you. I hope that the more people see me practising stimming, the more awareness, acceptance and opportunities there will be for everyone to practise self-regulation.

Mental health stakeholder input

In an interview, Professor Peter Enticott points out that autism is typically characterised within a biomedical model and diagnosed under criteria from the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM) or the World Health Organisation's International Classification of Diseases (ICD). Comorbid disorders of mental health are commonly diagnosed, particularly depression and anxiety. This model, while critical for

understanding the aetiology of autism and providing assistance where required, is focused entirely on deficits of autism, which can serve to stigmatise aspects of autism, such as stimming, that can otherwise be very functional for the individual (e.g., helping to regulate negative affective states and combat mental difficulties such as anxiety).²⁹ 'Stim Your Heart Out' and 'Syndrome Rebel' call into question the 'deficit' model of autism and can inform on different ways of enhancing one's experience of the world.

critical philosophical reflections

Mental health stakeholder reflections

Having worked in autism for almost twenty years, Enticott offers further critical reflection on some of the big frustrations he has encountered in the broader community, which include: a lack of understanding as to the nature of autism; continual stigmatisation and stereotyping; and a failure to accept or recognise anything that's not considered part of the 'mainstream,' a category that seems to be getting narrower and narrower. For Peter, his work is really about how we regulate our own behaviour and our emotional experience, which is a huge part of mental health. Different people have different ways of achieving this self-regulation; some ways are more harmful than others, but there are many important, positive experiences that we all seek for the same purpose, even if the actual expression is different.³⁰

Stimming is not particularly well addressed by current cognitive theories of autism, which include 'theory of mind' (i.e., interpreting others' mental and emotional states),

'executive dysfunction' (i.e., difficulties in cognitive abilities that allow goal-directed, purposeful behaviour), 'weak central coherence' (i.e., an emphasis on processing stimulus detail at the expense of the broader environmental context), and 'predictive coding' (where perceptual decision making involves a balance of knowledge about the world, or 'priors,' and sensory input).

From a cognitive perspective, stimming is often spoken about with respect to 'perseverative behaviour' (e.g., a maladaptive lack of behavioural inhibition); but from the perspective of these projects, stimming is perhaps best conceptualised within an emotion regulation framework, where sensory input produced from stimming behaviour serves to provide a means for down-regulating emotional arousal (particularly negative emotional states). Stimming can also be seen as from a communicative perspective, particularly where it involves vocalisation.

Performance reflections

'Syndrome Rebel' has now been performed three times, initially being created and performed for the MCA Artbar in Feb 19, curated by Lara Merrett,³¹ then at *BoK2019*,³² and most recently for my master's ADR Examination Exhibition³³ (Figures 03 and 04). At MCA Artbar, it felt gratifying to have an audience of people watching my performance. I felt that they were not judging my stimming in a negative way. Everyone in the room seemed relaxed and watched with interest. I was so excited to have a space to be able to share stimming where I knew, in the social constructs of the gallery (in comparison to

the social constructs of society in general), that I had people who knew they were coming to see a performance. There's a perimeter that's created by the mat that I stand on. It's an autism safety zone, a stimming zone, and I can walk on it knowing that I don't need to help anybody through that experience. I can just be free to stim. I was so excited, and that excitement came out in my performance and in my stimming and I was really energetic. And so, when I came off the mat, people said that they really experienced the joy in my performance.

Societal reflections

Stimming is like a signal going, 'I'm getting overwhelmed,' 'I need some quiet time,' 'I need some downtime, and I need to not get touched!' Our parents and family and educators all think that this behaviour is going to hold us back because of all the stigma that comes with it. If you are part of the disability community, you don't get as many opportunities. You won't get a job. You won't be able to participate in society the way that they really want you to be able to do; but it's actually those stigmas that are holding us back. I don't *have* autism, I *am* autistic. Every autistic person is different, and I'm the Prue version of autism. My art practice helps me understand the world and understand myself. I try to be like a reflection of society. It was really clear to me (in the mainstream K-12 school system) that there weren't really any avenues to places where I could express my emotions. It was clear that people just wanted me to bottle up my emotions. I left high school, thank goodness, and pursued my strengths and interests in art.

Art school reflections

In my studio at RMIT, I made a quiet room under my work desk (so I could have down time without having to go home). People think I'm upset when I have my meltdowns, so I can go in here and have some quiet time and let my brain have a rest. A meltdown is basically when my brain gets overloaded by information. The neuro pathways in my brain, there are a lot more of them. It means that my brain works five times harder than an average brain, with the expectation that I get the same processing time as a non-autistic person. My brain gets tired and shuts down. I've been told I can look scared or upset. I'm not actually scared or upset.

Eventually, I started to branch away from figurative work and go into more abstract expressionist works. I was also making 'By-product,'³⁴ my knitted work. Grandma taught me how to knit when I was young. When I was at art school, I made the connection between knitting and self-regulation, and then took that on as a (socially acceptable) form of stimming. I even saw a psychologist once and I said, 'I feel like I need to self-regulate and I need to get this energy out,' and she said, 'If you feel like that you can just sit on your hands, or if you're leaning on a wall, you can push energy into the room and no one will know that you're doing it.' So, she was teaching me tools of how to suppress and hide my autistic traits. After years and years of my parents and educators influencing me in that same way, I started to break free from that in my undergraduate time. I think that right now, it's really important to have words like 'autism.' However, one day, it would be great for us all to fall under the term

'neurodiversity' and then a word like autism wouldn't be needed to advocate for our access needs.

Lived experience reflections

There is a function to every stim. After thinking about it for a long time, I've realised that patting is one of my favourite stims. Patting has a very diverse range of functions that it can fulfil, and it is accessible in many different environments. For example, one function that patting can have is that if I'm in an environment and I'm unsure of what to do, I don't have a structure to work with, then patting say, a wall or some carpet, can create that structure for me to focus on. And then I feel really calm. If I'm feeling really overwhelmed, I can pat something, and it can help me regulate my emotions. When I'm hypersensitive or overwhelmed by one sensation that my brain's struggling to process, I can give myself positive sensory input by patting. And that's because of the way that patting interacts with my personal sensory profile.

My personal sensory profile means I am an avoider with some senses and a seeker with other senses. I'm hypo- or under-responsive to my sense of balance, which means I love to move. I love stims that activate my vestibular sense, such as jumping up and down, spinning, walking on my tip toes, rocking, and moving my head a lot. I'm hyper- or over-responsive to my sense of smell and also my sense of hearing, which means when my brain needs to process those sensations, it can become painful and make my brain work too hard and start to overload and shut

down. To prevent a meltdown, I can activate senses I'm hypo-sensitive in and give myself positive sensory input to combat negative sensory input. For example, if there is a smell that is really painful, or if there is more than one person speaking at a time, more than one sound source, or someone's talking and the TV is talking at the same time, my brain won't be able to selectively hear, and it will process both sounds at the same time. And then my brain will get overloaded. To help combat that, I can activate something like a patting motion, and that will help me to prevent my meltdown.

Reflections on the art process as theory

'Syndrome Rebel' raises the discussion of art as a process of social cognition and addresses the gap between descriptions of embodied cognition and the co-construction of lived experience. I believe this is the process to successfully break through the stigmas within society and create a path for the highly capable and willing autistic community to be more fully engaged and utilised. The focus of my works has been the sharing of my autistic strengths that emanate from my innate ability to self-regulate and manage the impacts of both extended detail focus and a widened sensory perception in a society not yet designed to accommodate for diverse neuro-types. Many of these reflections and more are expressed in my 'Perspective Shift' SBS On Demand TV Series³⁵ and Woman with Disabilities Victoria, 'Do Your Thing' Video Series.³⁶

In the future, I plan to continue my advocacy work through the arts, creating more stimulating works and gathering further data to support the 'Stim Your Heart Out' beliefs. Additionally, I am searching for a suitable collaborative organisation to help me develop a 'Stim Your Heart Out' curriculum for training in the benefits of stimulating/self-regulation.

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author biography

Prue Stevenson uses repetitive and tactile processes to allow for experiences of sensory play, creating spaces and opportunities for downtime. Working with oil, ceramics, textiles, sculpture, installation and performance, she advocates for the identity, empowerment and sensory awareness of the autistic community. She intersects with and collides against preconditioned stigmas and resultant systematic oppression and aims to celebrate and progress autistic culture for autistics, while creating experiences that are more broadly accessible. Prue is a practising fine artist, with a Bachelor of Fine Art (Expanded Studio Practice) and Master of Fine Art (by Practice) from RMIT.

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