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ORIGINAL ARTICLE

Autistic Reckonings with Eating Orders and Experiences through Art and Storytelling

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Abstract

This creative submission threads together academic literature and creative and artistic pieces created by four autistic individuals in response to the call for contributions to this special issue on Critical Eating Dis/order Studies. Autistic people often experience challenges with eating, through this is often pathologized in terms of eating disorders or as simply part of autism. Bringing together the emerging field of critical eating dis/order studies together with critical autism studies, our aim with this creative submission is to prompt dialogue and reflection on eating orders that impress upon and shape autistic lives, to surface the ways that eating orders entangle with ableism, neoliberalism and capitalism, and other normativities, and to begin to reimagine nourishment of autistic bodyminds. We each explored these themes through different modes of art and storytelling to surface and challenge eating orders and provoke further questions.

Keywords

Autistic, eating, eating orders, critical eating dis/order studies, critical autism studies, storytelling, art

History

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Introduction

We begin with the Call for Contributions for this special issue, which states that:

> Critical Eating Dis/Order Studies challenges the popular pathologization of people as "eating disordered" and moves our collective attention to questioning the normalization and celebration of eating orders that are hurting us. We have all experienced being ordered regarding what, how, when and why to eat, whether by family members, friends, social media, psychiatric "treatment", public health campaigns, architecture, celebrities, casual conversations, clothing restrictions, teachers, cultural norms, or billboard advertisements. What, how, when, and why we eat also

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> orders us on hierarchies of privilege and worth/value (i.e., superior vs. inferior). For example, we are told on mass scales that if we eat "right" we are "smart", "good", "civil", "clean", "responsible" and "healthy"
>
> Call for Papers, International Mad Studies Journal
> Special Issue on Critical Eating Dis/Order Studies

As autistic adults who have experience various eating differences, the Call for Papers for this special issue spoke to and stirred something in us. Autistic ways of being and doing in the world are most often pathologized through the psychiatric complex, not only through the deficit stories told about autism in psychiatry and reified through the Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnostic criteria for autism, but also in how our eating differences are pathologized. The integration of "Avoidant-Restrictive Food Intake Disorder" (ARFID) as a diagnostic category in the DSM in 2013 offered yet another avenue to pathologize eating differences that many autistic people experience, such as "avoidance based on the sensory characteristics of food" or "lack of interest in eating or food" (American Psychiatric Association, 2013, as cited in Keski-Rahkonen & Ruusunen, 2023). In addition, some autistic adults, especially those who are assigned-female-at-birth, discover they are autistic when they are labelled with an eating disorder such as "anorexia nervosa" or other related psychiatric eating disorder diagnoses. At the same time, while most of us are not necessarily labelled as "eating disordered" in the psychiatric sense, we may be labelled in other ways, such as "picky eaters", or as having "problem behaviours" around or problems with eating.

Eating is an area that can be particularly challenging for autistic people, regardless of whether or not they meet criteria for psychiatric eating disorder labels. It has been estimated that between 50% and 90% of autistic children and youth experience eating and feeding differences (Nygren et al., 2021); there is limited research on how eating and feeding differences are experienced by autistic youth and adults (Babb et al., 2022; Brede et al., 2020; Kinnaird et al., 2019; Park-Cardoso & D'Silva, 2021). Autistic eating differences are often understood clinically in relation to behaviourist narratives of "challenging behaviours" or "picky eating", with practices focused on moving toward normative eating "behaviours" (Bourne et al., 2022; Keski-Rahkonen & Ruusunen, 2023) that may result in increases in masking or distress. Typically, it is one's autistic traits, such as sensory sensitivities, rigidity and repetitive behaviours, executive functioning challenges, emotional regulation, and/or interoception difficulties, that are seen as responsible for autistic eating differences and it is these features of autistic bodyminds that need to be addressed (Bourne et al., 2022; Keski-Rahkonen & Ruusunen, 2023). While there is increasing attention to how eating environments also play a role in autistic eating (Park-Cardoso & D'Silva, 2021), limited attention has been given to the broader socio-material, discursive, and affective dimensions and systems that coalesce to enable or constrain autistic eating and how autistic youth and adults can thrive with eating differences; affirming supports and resources for autistic youth and adults to nourish their bodyminds are also limited.

Our aim with this creative submission is to prompt dialogue and reflection on eating orders that impress upon and shape autistic lives, to surface the ways that eating orders entangle with ableism, neoliberalism and capitalism, and other normativities, and to begin to reimagine nourishment of autistic bodyminds. In doing so, we bring the emerging field of critical eating dis/order studies into conversation with critical autism studies and feminist materialist disability studies. Critical autism studies is an interdisciplinary field of praxis that challenges deficit-based narratives of autism through advancing enabling, affirming, and accepting narratives, centers power relations within the autism field, and aims to remake theory and practice related to autism (Orsini & Davidson, 2013; Ryan & Milton, 2023). Recent developments in the field have also added as a core element centering the perspectives of autistic people in the field (Douglas et al., 2021; Ryan & Milton, 2023). We also think with the feminist materialist disability studies, specifically how embodied experience can be understood in terms of (mis)fitting, or "the degree to which th[e] shared material world sustains the particularities of our embodied life at any given moment or place" (Garland-Thomson, 2011, p. 596). In misfitting, bodymind-world entanglements, such as entanglements of autistic bodyminds and eating orders, are experienced in ways that are discordant, jarring, constraining, disabling, or even violent (Garland-Thomson, 2011; Rice et al., 2021). We contend that autistic stories of eating can open up possibilities for questioning and remaking eating orders.

We are a small collective of autistic storytellers, artists, academics, educators, and health and education workers based in Turtle Island, known in colonial times as Canada, who are using art and storytelling to explore autistic eating. All of us are connected in some way to the Re•Storying Autism Collective (https://www.restoryingautism.com/collective), an online autistic and neurodivergent arts, activism, and research collective with members across Turtle Island and internationally innovating in neurodivergent arts, and Autistic and neurodivergent led online accessibility. Taking the call for contributions for this special issue as a starting point, we each explored our own experiences with eating and relationships with food through art and story, using a variety of media.

We invite readers and viewers into this space in which we share our collection of stories and creative and artistic engagements with our eating experiences and eating orders. In doing so, we invite readers and viewers to consider engaging with the Re•Storying Autism Collective (2022) has called a "care-full neuro-crip reading" (p. 9). Guided by the reader/viewer, this practice may involve reading slowly, skipping parts, letting your body be in whatever way it needs to, or reaching out to someone you trust.

Creative and Artistic Contributions

This contains four contributions on our autistic eating experiences: (1) "Bon Appetit" by Kat Singer, a mixed technique textile artwork; (2) "Untitled Autistic Eating Story" by Elizabeth Straus, a multimedia story, or short video; (3) "sundance gave me my hunger back", by Claire Johnson, a mixed media sculpture; (4) "Untitled" by Paisley Worthington, a diary entry of

written text and graphics. Each contribution includes a statement from the artist about their piece. A brief analysis of themes across these pieces is presented in the section that follows all four contributions.

“Bon Appetit” by Kat Singer

I am a Toronto-based multidisciplinary artist, activist, educator and mental health worker.

I have alexithymia, a condition characterized by difficulty identifying and describing one’s emotions. I suspect that this is why I am drawn to unconventional ways of fleshing out what I am feeling, and also to mainly using shades of grey to convey my internal experiences. I have been creating monochrome fibre sculptures that explore complex emotional states since 2017.

Figure 1: "Bon Appetit" by Kat Singer. Image description: A frontal view of a textile art piece made of yarn hanging on a wall. The shape looks like a circle at the top and different pieces hanging down from the circle. Contained in the circle are shapes and lines meant to resemble organs in the abdomen. Hanging down from the circle are strings of black yarn and a light grey snake-like figure that looks like the large intestine. The colours are monochromatic with varying shares of black, grey and white.

“Bon Appetit” is a mixed-technique textile artwork that reflects the alienation from my body and its needs that I sometimes experience. I portrayed the mysterious workings of my sensitive digestive system using a collection of unusual, “alien” shapes.

My eating challenges have accompanied me all my life. My seemingly random and inexplicable food aversions have been a source of frustration for countless people, including myself. Being unable to eat what I am offered without an explanation that is acceptable to others has also had social consequences. The diagnostic label of Avoidant Restrictive Food Intake Disorder (ARFID) empowered me to continue seeking answers and figure out how to best nurture my body.

“Untitled Autistic Eating Story” by Elizabeth Straus

I am a queer, autistic, and disabled nurse, interdisciplinary researcher, and educator. My work involves bringing storytelling and the arts into research and community spaces to challenge stereotypes about disability, autism, gender, and sexuality. “Untitled Autistic Eating Story” (linked here; password: narrative) uses digital video – bringing together sound, words, and images to explore and reflect on my experiences with eating and center the deep entanglements of body and eating orders in producing eating (or not). I explore my experiences with labels and messaging about eating that flooded and stuck to my bodymind and the emotions and sensations that are central to my experiences of eating. In part 2, I reflect on the meal we call “lunch”, which has been a source of frustration and anxiety for most of my life, exposing the ways that the what, where, and when of lunch are ordered in ways that do not usually support and nourish my autistic bodymind. More recently, however, after accepting and affirming my autistic identity and working through some internalized ableism, I have come to a place of centering interdependence, rather than independence, in nourishing my body.

“sundance gave me my hunger back’, by Claire Johnston

Since I can remember, I've been rushed and taught to disconnect from my physical body. I crave slowness, contemplation, the ability to feel, and the ability to enjoy. For a time, ADHD medication helped me move at a pace the world demanded of me. A driver inside of me that would scream "GO, GO, GO." ADHD medication robbed me of my hunger, robbed me of my sacred connection to my body, to food, to water, to enjoy. This piece was created following my second year of a four-year sundance commitment. Sundance gave me my hunger and sacred connection to my body back.

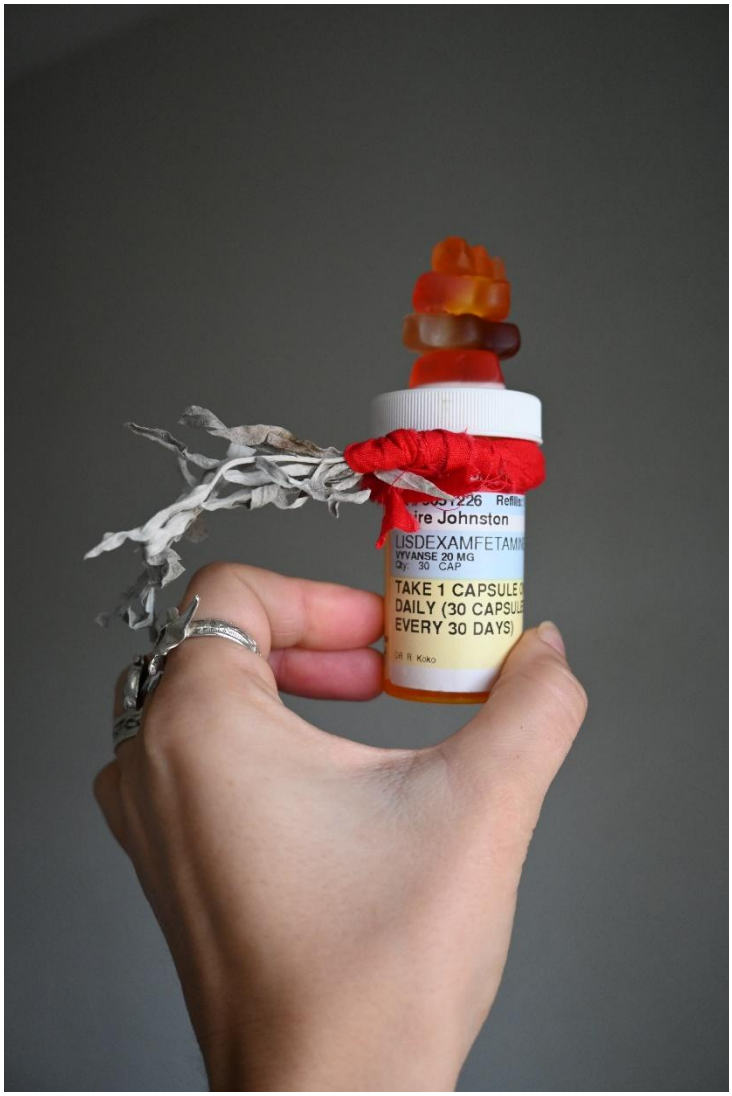

Figure 2: "sundance gave me my hunger back" by Claire Johnston. Image description: A hand holding an orange pill bottle with a white screw-on cap and a label that indicates the medication inside is Vyvance. Wrapped around the bottle just below the cap is a red piece of fabric and trailing off from the end of the red pieces encircling the bottle are wispy pieces of grey string. On top of the pill bottle, four gummy bears are stacked one on top of the other.

"Untitled" by Paisley Worthington

Paisley Worthington, an autistic graduate student in education, contributes a story of eating in a form similar to a diary entry with digital doodles splattered throughout.

I love food, all kinds. For me, cooking and eating are pleasant sensory experiences. The sequence of feeling and picking my groceries at the store (or better yet, the garden), washing the beautiful colours at home and cutting them into satisfying shapes. The trademark smell of each ingredient and how they come into conversation with each other in a recipe… a meal can feel like a masterpiece before you even have the pleasure of eating it. I am an autistic who has few challenges with selective eating. Rather, this entry in the special volume is more about **when** I eat than **what** I eat.

Knowing when to eat has a lot to do with the sensation of hunger. Interoception is one of the body's lesser-known senses, and it has to do with how we feel and identify sensations from within our body. In a single person, this sense can be overstimulated or understimulated, or sometimes it may alternate depending on the day. In my personal brand of autism, interoception is something I continue to learn about within my own body. For most of my life, I have not been able to identify physical sensations in my body, or, at least, I have been trained to ignore these feelings and can no longer label them accurately.

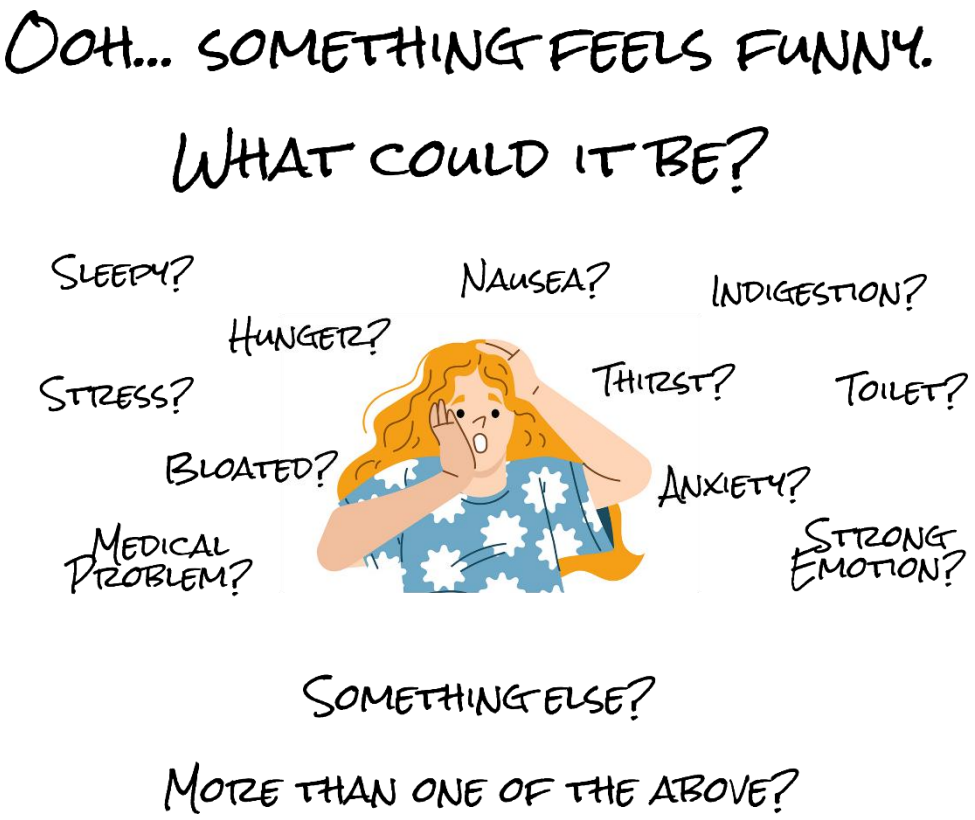

Figure 3a. Image description: A cartoon of a girl with long hair with one hand on her cheek and one hand on the top right of her head. Around her are words and phrases. First is the question "Ooh, something feels funny. What could it be?" then all around the image of the girl are possible answers: sleepy? hunger? nausea? indigestion? stress? thirst? toilet? bloated? anxiety? medical problem? strong emotion? And at the bottom two final options: something else? more than one of the above?

Attribution:
Clip art in Doodle 1 (shocked girl) from Image by upklyak on Freepik

Hunger and thirst are among many states that we identify through interoception, and once we realize we are hungry or thirsty we can do something about it. However, when we can't identify that "hungry" feeling, it is a lot harder to respond in real-time to our body's needs. If my stomach is like a gas tank, then hunger is like the "Fuel Low" signal that turns on when

the gas gets too low. The question is… when does that light come on? Do I notice it come on?

Figure 3b. Image description: A square with the words "fuel low" in the middle.

Some days my hunger light turns on when my tank is getting very close to empty. These are usually my busy days, or days when I find myself hyper focusing on a task to the point that my physical needs seem to fall away until they need urgent attention.

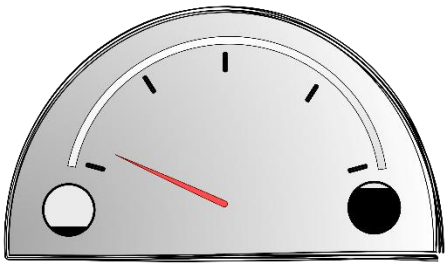

Figure 3c. Image description: A grey gas gauge with a red needle pointing just above the empty line.

Other days, my hunger light comes on when my tank is not full. This doesn't mean my stomach is empty, just that there is empty space in there. On days like these, something about the fuel already in the tank feels wrong; perhaps it is low quality food, or what I ate is already aggravating my sensitive digestive system (another condition common in autistics.)

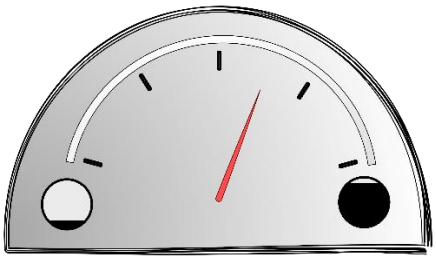

Figure 3d. Image description: A grey gas gauge with a red needle pointing somewhere between half full and three quarters full.

Interpreting these sensations is something we can get better at with practice. This takes time and patience to reflect and consider the variables at play: the activities my body has

already done today, the fuel I already gave it, and how it is feeling in this very moment. This process takes up space in the day, and quickly falls off the priority list when you are trying to make it in this neoliberal, productivity-driven life.

Most people who have been to university understand how demanding this life can be. In fact, many people who have to earn their keep and provide for themselves already know how busy this life can be. It is common for people, autistic and allistic alike, to juggle overloaded schedules, each with their own unique challenges.

When the calendar book is packed so tightly with commitments, mealtime stops being an embodied moment to pause and savour, and instead becomes another task to accomplish. Many folks are familiar with how the quality and source of our food changes in overwhelming situations (e.g., that we gravitate towards faster, more convenient foods), but let's talk about how the timing and quantity of food is impacted.

Let's look at an example: here is a sample agenda based on a typical undergraduate course schedule plus a part time job at a bar downtown – a common reality for students who need to earn money to afford university.

Figure 3d. Image description: A screenshot of a common university schedule with times on the left by the hour. Throughout are five classes, several labs, and 5.5 to 7.5 hour shifts of work scheduled. Nothing is scheduled on Sunday.

Now, the simple scheduling of course times and weekly shifts doesn't really capture the busyness that this lifestyle entails. Most people need to transport themselves to their workplaces, and many students in particular rely on public transit. In my university town, it is common for busses to be completely full, leaving you with no option other than to walk.

We also need to consider one of the basic requirements to keep a human body functioning: sleep. To schedule sleep time is almost laughable – as an insomniac, I know very well that sleep doesn't always come just because you want (or desperately need) it to. But for the sake of this entry, let's suppose you can sleep on demand.

With these considerations, a common university schedule ends up looking like this:

Figure 3f. Image description: A replication of the previous figure of the screenshot of a common university schedule with times on the left by the hour. Throughout are five classes, several labs, and 5.5 to 7.5 hour shifts of work scheduled. In addition, time is allocated each day for travel time to and from each event. Sleep is also scheduled each night as well as for 3 hours in the afternoon on Tuesday. Friday also shows a note to skip class in the morning in order to get 7 hours of sleep.

Reviewing this updated schedule, it is easy to understand how someone's needs can slip through the cracks. This schedule shows approximately 40 hours that lie outside of class time, travel time, work, and sleep. How would you spend those 40 hours?

Figure 3g. Image description: A clipboard with checklist. Unchecked boxes list grocery shopping, cooking/cleaning, eating, hygiene, homework, relaxing, social time, and dating.

Professors sometimes tell their students they should be ready to spend 10 hours per week studying and doing homework for each class they take. In this type of scenario, there are literally not enough hours in the week to accomplish everything. Many times, I have found myself having to choose between taking care of my physical needs and tending to my studies.

Some days it is really hard to know when to eat, and how much to eat. Certain scheduled activities, like lab time, do not permit any food or water in the area, and you cannot pause an experiment or a teaching session to have a snack.

Eating outside of the home also requires preparation and/or money. You can save money by packing a lunch, but to do this you need to have already shopped, cooked, portioned, and safely transported your meal and utensils to wherever you are going. Alternatively, if you have the funds, you can buy something to eat and hope that the lineups aren't too long.

When you work long days and are barred from snacking during particular times, you find yourself eating pre-emptively: "I'm not really hungry right now, but if I don't eat now I won't have another chance until 8pm …" Anyone who has experienced headache, light-headedness, or "hanger" due to lack of food or water knows how important it is to avoid these states. So, I find myself eating without regard for my interoceptive cues, disconnecting myself even further from my body. But on the bright side, I made it to almost all my classes!

Reckoning with and Challenging Eating Orders

Making our aut/artistic contributions opened up opportunities for reckoning with and challenging how we are ordered in terms of what, where, when, why, and how we eat. In this section, we offer some food for thought on the ways that eating orders show up in our art and stories and invite readers to join in dialogue about how autistic stories of eating might contribute to and expand our understandings of eating orders.

Each of us shared art and story that highlighted a common thread of how eating orders assume normative bodyminds – in our case, the neuronormative bodymind, and bodies whose material organ systems, such as the gastrointestinal tract as Kat centered in their piece, function in particular (normative) ways. In this way, we cannot understand eating dis/orders in critical ways without also acknowledging difference in bodily functions to begin with. Often, these differences become pathologized as something to be fixed, just like autistic and neurodivergent bodyminds are problematized and pathologized as something to be fixed (Douglas et al., 2021). Claire's art also speaks to the ways this pathologization can result in imposing "treatments," such as medications, that shape how the bodymind responds to hunger. This is not to say that medications should be avoided, but that analyzing experience through the lens of eating orders requires consideration of the deep entanglements between eating orders, bodymind sensations, and embodiment. We invite readers to consider how working *with*/*across* difference in ways of eating and bodily function could expand opportunities to challenge eating orders.

Our stories and art also bring into focus how neoliberal and capitalist societies contribute to eating orders. Paisley's diary entries and Elizabeth's multimedia story alert us to the ways that normative neoliberal (and ableist) understandings of time shape how we order our days, or

perhaps more accurately, how our days, our time, become ordered. The speed at which our neoliberal society moves privileges certain bodyminds, leaving other (non-normative) bodyminds behind. Many of us experience misfitting with normative neoliberal and ableist time (see for example, Kafer, 2013; Rice et al., 2023; Straus et al., 2024). When these normative expectations of how and when we use our time are imposed upon us, we may experience challenges with nourishing and nurturing our bodyminds. In this way, thinking with misfitting means that what is understood in clinical contexts as eating problems or eating disorders are not situated solely in the bodymind, but instead result from a discordance between bodymind and world that constrain opportunities for nourishing our bodyminds.

The impacts of misfittings of autistic bodyminds and worlds governed by eating orders also surfaced in other contributions. Elizabeth's multimedia story offers insights into misfitting of autistic bodyminds and where we eat or are expected to eat. In the second part of the video, they speak to the social expectations of eating lunch in the cafeteria in high school and how they misfit with the social-sensory space of the cafeteria in ways that only further constrained opportunities for eating. The sensory and social overwhelm weighed heavily on their bodymind as they tried to enact the social expectation of eating with friends in the cafeteria, which often led to not eating at all. They also speak to the messaging they received in childhood that continued to influence their eating practices throughout their adult life. Paisley's diary entries also speak to the immense energy drains many autistic people experience when taking on everyday tasks, like scheduling university classes and completing other daily living activities, that require much more time and energy than what our neoliberal society expects. Eating, in these contexts, may become something that needs to be fit into one's schedule like any other task during the day. Finally, Claire's art piece encourages us to consider how settler colonialism shapes eating orders, and how in connecting back to their Indigenous culture through sundance, they also came to know their bodymind and hunger again after years of struggling with eating and hunger in biomedical contexts.

Provocations

Rather than offer conclusions, which imply a finality, we wish to keep the meaning of, and dialogues about, autistic eating and eating orders open and moving. Therefore, we leave readers with several provocations for future dialogue, analysis, and research that have surfaced from our engagement in storytelling and art about our experiences of eating.

- In what other ways do our contributions surface and challenge eating orders that shape autistic experiences of eating?
- How are these experiences also gendered?
- What opportunities open up through engaging with autistic stories through the lens of eating orders?

- How can the lens of eating orders complicate our understandings of differences labelled as “Avoidant-Restrictive Eating Disorders” in autistic people?

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