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Enmeshing Selves, Words and Media, or Two Life Writers in One Family Talk about Art and Disability

Abstract: Two life writers in the same family – one neurotypical, one autistic – converse about the mountain of material they’ve produced: poems, memoir, essays, scholarship, and documentary films. Preferring to conceive of their work as interdependent and enmeshed, not bound by the strictures of identity politics and thus separate or conflicting, they advance a neurocosmopolitan and rhizomatous understanding of the self in words. David James (“DJ”) Savarese is an artful activist, writer, teacher, and Co-Chair of The Alliance for Citizen-Directed Supports. An OSF Human Rights Initiative Youth Fellow (2017–2019) and co-producer, narrator, and star of the Peabody award-winning documentary *Deej: Inclusion Shouldn’t Be a Lottery*, he publishes poems, creative nonfiction, and scholarly essays. Ralph James Savarese has authored five books and co-edited three collections, including the first on neurodiversity. He has received awards from the Herman Melville Society, the National Endowment for the Humanities, and the Mellon Foundation, which funded a neurohumanities fellowship at Duke University’s Institute for Brain Sciences.

Keywords: life writing, disability, neurocosmopolitanism, narrative ecology, collaboration, documentary, textocentrism

Ralph James Savarese: In the final poem of my recent pandemic collection, *When This Is Over*, I write in the voice of my 28-year-old son. He is autistic; he uses a text-to-voice synthesizer to communicate; and the pandemic has been especially hard on him, as it has wildly curtailed the fully inclusive life that he fought so hard to build and maintain. In many ways, the pandemic has made shut-ins of us all – or at least those who have practiced social distancing with a nearly religious fervor. Here’s the poem:

“Gate Agent”

The gate agent from hell – that’s you, Dad.
A veritable Cerberus, hound of Hades,
you got snakes coming out

of your butt and oversized belly.
Your serpent's tail needs a good waxing –
and get a haircut while you're at it.
Who could ever want three heads?
Overthinking and over-smelling everything...
You're charging extra for rollaboards;
you're not letting dead families sit together;
you're barking into the microphone.
How about a little customer service?
Those of us in Abraham's bosom,
those of us wearing a pine overcoat,
those of us picking turnips with a step ladder
or basting the formaldehyde turkey,
we're tired, Dad. Cut us some slack.
Who cares if terrorists rush the cockpit?
We're as terror-stricken as we could be.
I just want to go out onto the front lawn
of life and wave at the cars.¹

I have been as bad as this imaginative evocation of my son's point of view suggests. We live in downtown Iowa City, and my son watched one mask-less young person walk by our house after another. Any time he even approached the front door, I would start barking. (Imagine that other Italian – Dr. Fauci – foaming at the mouth, and you'll get the picture.)

While the poem is critical of me, it's also presumptuous. My son is a published poet and nonfiction writer; he can certainly speak for himself. In fact, I've devoted my life to giving my son a voice. Labeled “profoundly retarded” when my wife and I adopted him at age six from foster care, he and a number of other nonspeaking autistics have forced scientists to rethink the so-called “severe” end of the autism spectrum. He was educated in regular classrooms, went to Oberlin College as its first nonspeaking student with autism, graduated Phi Beta Kappa. Once, in an interview with Dr. Sanjay Gupta on CNN's “Anderson Cooper 360,” he responded to the question “Should autism be treated?” by typing, “Yes, treated with respect.”²

So, it's bad enough that a father is speaking for his adult son. Still worse that a non-autistic person is speaking for an autistic one. And yet, we have each done this to the other. My son turned my first book, *Reasonable People: A Memoir of Autism*

1. Ralph James Savarese, *When This Is Over: Pandemic Poems* (North Liberty: Ice Cube Press, 2020), 86.

2. CNN Transcripts, *Anderson Cooper 360, Finding Amanda*. Aired April 2, 2008. Accessed May 4, 2021. <http://transcripts.cnn.com/TRANSCRIPTS/0804/02/acd.02.html>.

and *Adoption*,³ into a play, *Plotting Hope*,⁴ re-imagining his father as a character. I remember watching myself on stage – both through the lens of the book I had written and through the lens of my son’s reimagining. *Reasonable People* ends with a chapter written by my son called “It’s My Story!”⁵ The chapter takes me to task for, among other things, being too kind to his birthmother. Because she was so unspeakably abusive, she didn’t deserve, he believed, my liberal sympathies regarding welfare and drug addiction.

My son has also written about me in poems and essays, including one called “Passive Plants,” in which he presents himself as a tutoring vine:

If I had conceived of my adoptive mother and father as potential parents, I never would have believed in that future. Instead, I started climbing. I felt myself wrapping around them. I felt the sturdy bark of their brains, the sweet pulp and marrow of their hearts. They needed to learn how to be vines, and so I taught them. Together, we unmade the idea of *tree*. Let us speak from this moment forward of a *family vine*: not descendent branches but a loose collective of stray seeds. A garden that isn’t a garden, embracing the wind.⁶

He adopted us, he claims, and in the process reinvented kinship. Notice how hard he pushes back against the do-gooder trope of liberal salvation:

People think of my parents as saints. They cannot see how I saved them. Together, we became whole in a holey sort of way. The weed can reclaim both the devastated field and the lawn of an upscale home. As Jonathan Skinner says, “From an ecological standpoint... weeds are a necessary part of the healing process.”⁷

In his telling of our family story, the wind and a seed make something new.

Perhaps, most notably, my son wrote about me in his film *Deej*, which tracks his inclusion journey from high school through his first year at Oberlin.⁸ The film appeared on PBS and won a Peabody Award. Once again, I found myself staring at a version of myself, my dadness, this time on a screen. My son wrote and co-produced the film; he had complete control over the words and 50% control

3. Ralph James Savarese, *Reasonable People: A Memoir of Autism and Adoption* (New York: Other Press, 2007).

4. David James Savarese, *Plotting Hope*. “Readers Theatre,” Grinnell High School. Grinnell, IA, 2009.

5. David James Savarese, “It’s My Story,” *Reasonable People: A Memoir of Autism and Adoption* (New York: Other Press, 2007), 432–442.

6. David James Savarese, “Passive Plants,” *Iowa Review*, vol. 47, no. 1 (Spring 2017), 35.

7. Savarese, “Passive Plants,” 36.

8. Robert Rooy, *Deej*, Rooy Media, 2017. The film’s web site can be found here: <https://www.deejmovie.com/>. The trailer can be found here: <https://www.deejmovie.com/#watch-trailer>.

over everything else. When you're collaborating with three filmmakers, two of them executive producers, and interfacing with a huge government funding entity, you quickly discover the limits of film-by-committee. Nondisabled people have so invested in the narrative of overcoming that it's difficult to maneuver them out of Disney-like stereotype. Although my son mostly approves of the film, we both encountered a version of our feisty selves pressed into the service of a simple plot.

Alison Kafer has urged disability studies scholars and writers "to make our lives part of our arguments."⁹ As a very public autism family in the US, we have done just that: wedded life writing in multiple genres, from multiple points of view, to an activist impulse. How can we use our extraordinary privilege and good fortune to make a difference in the lives of other autistic people, especially those who don't speak? How can we do the same for foster children? In what follows, my son and I explore, through dialogue, the now mountain of material we have produced over the last fifteen years. How best to describe this simultaneously separate and collective endeavor?

In *The Co-authored Self: Family Stories and the Construction of Personal Identity*, Kate C. McLean speaks of "narrative ecology," a dynamic space in which stories cross-pollinate and co-produce the selves within that space.¹⁰ Judith C. Lapadat, in "Ethics in Autoethnography and Collaborative Autoethnography," imagines a "multivocal" approach that purposefully makes room for differences of opinion and points of view.¹¹ In my recent book, *See It Feelingly: Classic Novels, Autistic Readers, and the Schooling of a No-Good English Professor*, I use the metaphor of "conjoined neurologies" to capture the process of reading and discussing literature across neurotype.¹² Identity politics have encouraged us to police the borders of representation – and with good reason – but it has come at a cost: namely, a sense of collaboration and collectivity, however fraught. What connects us as we explore matters of difference? This is not a longing for old-fashioned humanism and universal values. Rather, it's a call for interlocking and interdependent stories, proliferating lives in print.

David James Savarese: I'm for pushing beyond borders in *every* direction. Ours is not a story of multivocality; it's a story of multimodality. It's not a story

9. The characterization belongs to Jennifer Fink, *All Our Families: Finding Our Disability Lineages* (Boston: Beacon Press, 2022). See Alison Kafer, *Feminist, Queer, Crip* (Bloomington: Indiana University Press, 2013).

10. Kate McLean, *The Co-Authored Self: Family Stories and the Construction of Personal Identity* (Oxford: Oxford University Press, 2016), 5.

11. Judith Lapadat, "Ethics in Autoethnography and Collaborative Autoethnography," *Qualitative Inquiry*, vol. 23, no. 8 (2017), 589.

12. Ralph James Savarese, *See It Feelingly: Classic Novels, Autistic Readers, and the Schooling of a No-Good English Professor* (Durham: Duke University Press, 2018), 15.

of a shared narrative or space; it's a mesh of emotional, physical, intellectual, artistic, and/or activist entanglements whose traces live on in some filmic, dramatic, memoiristic, dialogic, or scholarly – but just as often lyrical, poetic, and metaphorical – expression. We're opening up a multiplicity of unfolding possibilities rather than upholding static, stagnant, and singular identities. It's not about competing versions of the same life story; rather, our lives are entangling and enmeshing, not defining and confining. In an ever-unfolding universe, there's room for everyone, every kind of kin.

And while we might both use words to leave traces of our journeys, in fact our love for each other exists first and foremost in a modality beneath and beyond words. We found ourselves, formed our us-ness, not linguistically but physically.

In *Reasonable People*, you wrote:

The first time I met the three-year-old boy who would become my son we butted heads. Without any eye contact at all, without any animosity, without anything that could be construed as emotion, he took me by the second finger on my right hand to the couch in the family room, waited for me to sit down, sat down himself, and then brought our two skulls swiftly together. Emily, who was standing in the doorway, was as surprised as I – surprised that he'd even registered my presence, let alone that he'd approached me, doubly surprised the encounter was so intimate, so physical, so literally heady.¹³

You then use a metaphor of animal entanglement. Two sets of antlers find one another:

Working professionally with DJ, Emily had seen him use his head as a battering ram when angry, but she'd never seen him use it as a form of introduction: a forceful, but comparatively measured, hello. In fact, she'd never seen him seek out such close contact with anyone before. This version of an embrace – our two foreheads joined by the pressure of his tiny hands – left me dazed, a dull ache emanating from just above my nose. I was unprepared for the superfluousness of eyes, the heaviness of a child's breath. For twenty minutes we stayed that way: two bighorn sheep fallen asleep in play or combat.¹⁴

I love that I lured you out, too, Dad, and not just the other way around. How much of this sort of thing gets into life writing? The form is typically so oriented to “events,” to things that happen – not to sensation. In my film *Deej*, my non-autistic co-producer couldn't conceive of a plot that might be rooted in the body – my body, my way of perceiving. For him, it was simply a matter of “Will DJ make it at Oberlin?”

13. Ralph James Savarese, *Reasonable People: A Memoir of Autism and Adoption* (New York: Other Press, 2007), 31.

14. Savarese, *Reasonable People*.

Later, in college, I'd capture another of our wordless exchanges in the form of a pantoum:

"My Adoptive Father Buys a Trampoline"

Like newly laid asphalt,
the black mat baked in the Florida sun
at once taut and spongy.
This ridiculous highway,

which sat baking in the Florida sun,
afforded my father and me
the most ridiculous of highs.
We bounced up and around,

my new father and I,
on this improbable racetrack –
up, up and around, bouncing,
like Herbie, the Love Bug,

his racetrack just as improbable
as ours. My new name –
not Herbie, the Love Bug –
hugged me like a guardrail.

A new Italian last name
was just what a foster kid needed,
hugging me like a guardrail
On newly laid asphalt.¹⁵

In a pantoum, the second and fourth lines of a stanza become the first and third lines of the next stanza, with the final line of the poem repeating or echoing the first. The lines, you might say, are ever-entangling; and ever-changed by those entanglements. The poem is obviously not just about jumping. In it, I use the sounds of the words and lines and the quasi-refrains to convey the wordless dialogue of movement between us. Repetition anchors life and, in so doing, becomes ritual – reassuring ritual. The "spongy" surface of the trampoline offered feedback to our bodies. I might even call it proprioceptive love. Again, how much of this sort of thing makes its way into life writing?

Since I wrote that pantoum in my early years at Oberlin, two words I've dropped from my vocabulary are "adopted" and "adoptive." As my poem makes clear, I *used* to think of us this way, but now whenever you refer to me as your "adopted son," I feel a prick of sadness. And while I think you use it as a kind

15. David James Savarese, unpublished poem, 2014.

of message that you *found* or *chose* me, that you *elected* not to have biological children, in fact your recounting of our first meeting makes clear who made the first move. At the very least, aren't you the *adopted* father and me the *adoptive* son? To me these words feel like relics of the past I bid farewell to in my lyric essay "Passive Plants." As you just wrote, "In [my] telling of our family story, the wind and a seed make something new." I prefer to think of us this way: organic, alive, dynamic – paying no heed to manmade identities.

Ralph J. Savarese: In "Don't Mourn for Us," which some people consider the beginning of the neurodiversity movement, Jim Sinclair writes, "Parents often report that learning their child is autistic was the most traumatic thing that ever happened to them. Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle."¹⁶ With his title, Sinclair, who is autistic, directly addresses such parents, hoping to disrupt this dominant plot. He then says crucially, "This grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have."¹⁷ I was no doubt freed from dashed expectations – as both a dad and a memoirist. I wasn't going to write a book like Mark Osteen's, which attempts to justify the institutionalization of his autistic son at age 12,¹⁸ or like Kim Stagliano's, which narrates the aberrant potty habits of her autistic children – what I call "the rhetoric of pee and poo" – to give grief an intolerable cast.¹⁹ I knew you were autistic, I knew you didn't speak, I knew the label that had been attached to you ("mental retardation"), but I also knew, back then in an unsophisticated way, that the expert view of autism didn't match what I was seeing. It certainly didn't match the immediate bond we had developed.

I was also freed, as a dad and memoirist, from the typical adoption plot. Ours was an open adoption (I know you hate that word!), and I had, still have, no objection to you "finding" your birth parents, though obviously it's complicated by abandonment and abuse. As you know, we initially supported your birthmother's reunification efforts, paying for drug rehab and a place to live. I'm drawn to your description of us as "paying no heed to static, manmade identities that seek to confine us." I think that's true inside our house and on the page to an extent, but in public, people are all too ready to impose identities on us.

16. Jim Sinclair, "Don't Mourn for Us," Autism Network International (ANI) Newsletter, *Our Voice*, vol. 1, no. 3 (1993). Accessed May 4, 2021 at https://www.autreat.com/dont_mourn.html.

17. Sinclair, "Don't Mourn for Us,"

18. Mark Osteen, *One of Us: A Family's Life with Autism* (Columbia: University of Missouri Press, 2010).

19. Kim Stagliano, *All I Can Handle: I'm No Mother Teresa: A Life Raising Three Daughters with Autism* (New York: Skyhorse Publishing, 2010).

Even essential books such as *Allies and Obstacles: Disability Activism and Parents of Children with Disabilities*²⁰ or *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew about Growing Up, Acceptance, and Identity*²¹ posit a significant divide between autistics and non-autistics. In this age of identity politics, we find it difficult to imagine a form of intimacy that not only reconfigures difference but also leads to something like anthropological, maybe even neurological, hybridity. Remember when, as a boy, you typed, “Really hoping that very nervous Dad is autistic”? Sometimes I think that the neurotypical fondness for categories, for generalization – we’re top-down processors, after all – has forced everyone to think of language, in the words of Dawn Prince, “as a weapon rather than an amorphous mist of the birth waters of reality.”²² “Words,” she maintains, “cut up the world, and... also... cut groups of people one from another.”²³ The freedom that we’ve carved out, DJ, is a privilege, but it’s both limited and uncertain.

As a scholar, I’ve written extensively about neurocosmopolitanism, a term I coined (Nick Walker coined it independently as well) to capture the idea of neurological hybridity.²⁴ I may not be autistic, but having embraced autism and lived with someone who is – you! – having become beautifully “entangled” with it, I am like an expat in Paris or Rome or Quito or Beijing. Autism has rubbed off and in, changing me – for the better. I borrow this conceit from your poem “The Unmerited Favor of Light,” where you say that you now “live abroad in language” and worry

20. Allison C. Carey, Pamela Block, and Richard K. Scotch, eds., *Allies and Obstacles: Disability Activism and Parents of Children with Disabilities* (Philadelphia: Temple University Press, 2021).

21. Emily Paige Ballou, Sharon daVanport, and Morenike Giwa Onaiwu, eds., *Sincerely Your Autistic Child: What People on the Autism Spectrum Wish Their Parents Knew about Growing Up, Acceptance, and Identity* (Boston: Beacon Press, 2021). These books provide a crucial service, but they assume relatively fixed identity roles. Autistics and non-autistics can each become more aware of the other, but the divide remains.

22. Dawn Prince, “The Silence Between: An Autoethnographic Examination of the Language Prejudice and Its Impact on the Assessment of Autistic and Animal Intelligence,” *Disability Studies Quarterly*, vol. 30, no. 1. <https://dsq-sds.org/article/view/1055/1242>.

23. Prince, “The Silence Between.”

24. Ralph James Savarese, “From Neurodiversity to Neurocosmopolitanism: Beyond Mere Acceptance and Inclusion,” *Ethics and Neurodiversity*, ed. C. D. Herrera and Alexandra Perry (Cambridge: Cambridge Scholars Publishing, 2014). Ralph James Savarese, “I Object: Autism, Empathy, and the Trope of Personification,” *Rethinking Empathy*, ed. Meghan Marie Hammond and Sue Kim (New York: Routledge, 2014). Ralph James Savarese and Lisa Zunshine, “The Critic as Neurocosmopolite,” *Narrative*, vol. 22, no. 1 (2014). Ralph James Savarese, “Toward a Postcolonial Neurology: Autism, Tito Mukhopadhyay, and a New Geo-poetics of the Body,” *Journal of Literary and Cultural Disability Studies*, vol. 4, no. 3 (2010). Ralph James Savarese, “What Some Autistics Can Teach Us about Poetry: A Neurocosmopolitan Approach,” *The Oxford Handbook of Cognitive Literary Studies*, ed. Lisa Zunshine (Oxford: Oxford University Press, 2015).

that you've lost your "native eye," that keen attachment to the sensory.²⁵ I don't dismiss this fear at all, but maybe the notion of gain and loss occludes the fact that we are never just one thing purely. Interaction and relation govern life. Rigid identities can only be static.

I define neurocosmopolitanism as "being respectfully at home with all manner of neurologies," and I envision a kind of endless movement toward, and interaction with, the Other.²⁶ In a number of essays I suggest that poetry is a hospitable – indeed, a neurocosmopolitan – meeting place for different neurotypes. And there's research to back this up. For example, autistic people excel at hearing the perceptual aspects of language, all of that pre-categorical auditory information that gets discarded in the process of manufacturing phonemes; non-autistics, in contrast, excel at meaning, at making sonic generalizations that narrowly signify.²⁷ Of course, in poetry semantics must collaborate, must enmesh, with sound. Each becomes the other through intricate pattern.

Somewhere, you say that poetry was your first language, and I still remember, very early in your linguistic emergence, what you typed on your computer after I read aloud Dylan Thomas's poem "Fern Hill." "Very great sound, very great sound," you said. Words can be like birds in a tree or the wind in a field – they need not mean. And certainly Thomas pushes the limits of literal understanding. Once, after enduring a long car ride with your parents to visit your grandmother – we were bickering about directions – you typed, "Yes. Yes. Mom and Dad. Long time. Very married." The two-beat rhythm was as important, I remember thinking, as the witty commentary on our romantic life. To return to your pantoum, poetry was like a trampoline: semantics were superfluous but also emergent: just part of a bouncy, metered pair. A long time ago you asked, "Why is poetry to the side of life? Why don't we request a drink in a catchy way?" Good question!

So, I'm thinking about collaborative life writing on all sorts of levels, and I'm wondering about your film. About three-quarters of the way through, tensions with your non-autistic co-producer erupt, becoming part of the narrative. Filming stops, and you must both regroup. You've said that the camera could only stare at you in the way that people stare at those with disabilities. Your partner's commitment to "cinema verité" threatened to become a freak show. Eventually, you arrived at a compromise of sorts: the narrative of "making it" at Oberlin would

25. David James Savarese, *A Doorknob for the Eye* (Minneapolis: Unrestricted Interest Press, 2017), 16. <http://www.djsavarese.com/3d-flip-book/doorknobfortheeye/>.

26. Ralph James Savarese and Lisa Zunshine, "The Critic as Neurocosmopolite," *Narrative*, vol. 22, no. 1 (2014), 20.

27. Ralph James Savarese, "What Some Autistics Can Teach Us about Poetry: A Neurocosmopolitan Approach," *The Oxford Handbook of Cognitive Literary Studies*, ed. Lisa Zunshine (Oxford: Oxford University Press, 2015), 403–404.

be punctuated by four of your poems set to the astonishing oil paint animation of Em Cooper.²⁸ Rewatching the film, I thought to myself, *Documentary realism is like most academic prose, and oil-paint animation is like poetry*. That's overdoing it, I know. But you've said that in those ekphrastic sequences, your fluid, sensuous inner world comes through. Staring stops. Could you say a few words about collaborative media and your work with Em Cooper in the context of life writing? Also, the collective you formed in Iowa City?

David J. Savarese: I'm glad to talk about poetry, Dad. As you know, my relationship to language has always been complicated. You've written about it in any number of places. On the one hand, I agree with Dawn Prince, static binaries are often employed to divide, to separate: verbal/nonverbal; speaker/nonspeaker; autistic/non-autistic. If I'm honest, when you use them, a part of me cringes. On the other hand, "neurocosmopolitan" offers an unbounded, ever-expanding field of diverse communion. And I agree with you, poetry offers us neurocosmopolites a common, open meeting ground.

In that same essay, Dawn Prince says the following of language:

[...] language was like food: each word was onomatopoeic and tasted and smelled, even sustained me as a whole thing of its kind. I digested words, sentences and stories as if my life depended on it. Again, like food, I saw language as a necessary element for survival and a web of interdependencies.²⁹

Can I say that, together, Em Cooper and I created a kind of neurocosmopolitan dialect/diet of poetry-and-oil-paint-animation? And that it's multisensory, multivocal, non-logocentric, non-textocentric, collaborative expression was purely liberating? Poetry was asked to paint, and painting was asked to play the drums – to keep rhythmic time. Em Cooper's animation made my poetry dance. Together, the two art forms sucked us all into a space where motion, rhythm, pattern, color, sound, and texture freely conversed, inviting us back into the world of trampolining.

Ahhh, to be back in a world of discussions in motion, but truth be told, Em met me first in words. She read every paper and poem I'd written in my time at Oberlin. An ocean between us – she lives in England – she'd g-chat with me, learning the cadence and rhythm of my written speech. And rather than illustrate the poems, images from my writing – of volcanoes, flags, and vines – surface, melt, then disappear, only to resurface in the next poem. The viewers are literally

28. Examples can be found here: <https://www.deejmovie.com/poetry>.

29. Dawn Prince, "The Silence Between: An Autoethnographic Examination of the Language Prejudice and Its Impact on the Assessment of Autistic and Animal Intelligence," *Disability Studies Quarterly*, vol. 30, no. 1 (2010). <https://dsq-sds.org/article/view/1055/1242>.

swept into the vortex and back out again. Without her wordless encouragement, her sensory accommodation, the viewers' transformations would not have been complete.

Documentary realism can capture my challenges the way someone passing by a wreck might rubberneck, but it can't capture my rich inner life. Nor can it unfix the "I" who loves to stand apart and stare at difference. And so, if we're talking about life writing, we need to remember other, collaborative methods of relating a life.

Our culture practices a form of close-mindedness that favors or privileges written language over other means of communication, what scholars call "textocentrism." As Cassandra Hartblay points out, the consequences are significant:

[T]extocentrism [...] reinforces racial and class domination,...[and is] also a primary field in which ableism is inscribed. Textocentrism privileges particular modes of cognition over others. This is not to say that texts in general, or textual analysis must be abandoned; rather, that they must not be elevated so as to obfuscate [or hide] other ways of knowing, particularly, of *performative* interactions.³⁰

Four-fifths of the way through my anthropology thesis at Oberlin – an autoethnographic exploration of ethnography and language – I suddenly became mindful of my own bias. A high achiever in mainstream education from kindergarten through college, I now communicated almost entirely in written English. What, I wondered, might I have pruned or suppressed in the process? I began to seek out the works of those autistics – some nonspeaking, others not – who choose nonalphabetic forms of expression. In an ekphrastic series of poems titled *A Doorknob for the Eye*, I turned my attention to the artwork of seven autistic artists and sought to converse with them in poetry.

As you say, I initially framed my dependence on language as the loss of my "native eye," but I came to see that I was "dividing up" the world, as Prince would say. I remember you telling me about a study that looked at how literate autistics and literate neurotypicals remember letters.³¹ The former group remembers them as shapes, as if they were looking at art; the latter, names them. In other words, the incidental curve of the "p" or "o" plays no role in the neurotypical's relationship to language. It's just a random part of the signifier. You said, recently in a talk

30. Cassandra Hartblay, "This Is Not Thick Description: Conceptual Art Installation as Ethnographic Process." 2016 Paper Presentation for the Symposium on Innovations in Ethnographic Methodology. Berkeley, CA: UC Berkeley Center for Ethnographic Research.

31. Hideya Koshino et al., "Functional Connectivity in an fMRI Working Memory Task in High-functioning Autism," *Neuroimage*, vol. 24, no. 3 (2005), 810–821.

at Duke, that “in autism maybe there’s no need for ekphrastic reconciliation. Poetry is painting before the poet even starts.”³²

This past summer, boxed in by the pandemic, I once again found myself stuck. Yearning for the openness and fertile soil of neurocosmopolitan space, I invited three of my poet-friends,³³ now scattered around the country, to ekphrastically connect with the artwork of Malcolm Corley who is autistic.³⁴ Originally, I intended to write the book myself, but I soon realized doing it collectively would not only enrich the conversation but also create an expansive and neurocosmopolitan community – making a solitary activity more fun, especially during the pandemic, and adding connections to each of our lives. These connections and relationships might grow in multiple unforeseen ways in the future. *Studies in Brotherly Love* will come out this year from Prompt Press,³⁵ which specializes in ekphrastic poetry, and even it will refuse to be ordinary, singular. The book is an art object in and of itself: handmade, from start to finish, and having only a limited number of “copies.” In one of my poems, I remember getting the stomach flu the first Christmas I spent with you. You held my head as I vomited – yet another form of enmeshment!

This summer, working and teaching from your room inside our house, you abandoned academic writing and rediscovered your poetic voice – your/our life pouring out in four books of poetry, two intimate collaborations with close friends: one a poet, the other, an artist and musician. Tell me, Dad, what is it that poetry offers *you* that no memoir, no op-ed, no scholarly essay ever could?

Ralph J. Savarese: As you know, DJ, I have an MFA in poetry and a PhD in literature; my job at Grinnell has me teaching both creative writing courses and literature ones. Small liberal arts colleges can’t afford to field faculty with narrow specializations. I’m very grateful that I haven’t been forced to teach, and do, just one thing. Just as you and I and our various forms of life writing are entwined, so is my own memoir, poetry and scholarship. Like people, genres can become self-obsessed or narcissistic. (There’s an old joke: what does the memoir specialize in? Me!) They need a corrective. So, I’m glad to be constantly pulled out of one way of approaching things. But to answer your question, poetry offered a kind of emotional compression and urgency. These things seemed almost laughably suitable to the pandemic. The language could be fluid and inventive, yet it all happened in a box. The words, as it were, couldn’t go outside.

32. Ralph James Savarese, “The Discourse of Heterogeneity and ‘Many Outcomes’ in Autism: What Ends Does It Serve?” Duke University, April 2021.

33. www.clarettaholsey.com. <http://lateefmcleod.com>. <https://jorrellwatkins.com/>.

34. <https://malcolmstiles.com/>.

35. <https://promptpress.org/>. <https://www.jazgraf.com/>.

I'm concerned that readers might think our vision of enmeshment is all sunshine and roses, without conflict and challenges, so I want to be sure to address, in this final part, how differences of perspective loosen, not dissolve. In a piece called "Coming to My Senses," which blends a reading of Thoreau with theories of autistic perception, you reveal a limitation of my nearly rabid pro-inclusion philosophy.³⁶ In fact, you explicitly update my piece "River of Words, Raft of Our Conjoined Neurologies."

That piece recounted the process of reading *The Adventures of Huckleberry Finn* with you during your junior year of high school. I was quite concerned about how you would react to Twain's narrator, who is terribly abused – in fact, almost killed – by his father and then later adopted. You were really working through your own trauma at the time, and reading seemed to aggravate it. My piece celebrates the emergence in you of a kind of aesthetic distance, a writerly orientation to the text. How was it constructed? How does it work? Your AP English class became, in your words, a kind of "safe house," and I depict you, the only fully included, nonspeaking student with autism in Iowa, as guided by the spirit of Harriet Tubman, your hero, through the halls of Grinnell High School. (I've always loved your line "smart self's walk down freedom's trail.")

But reading your piece, I had to confront a stark fact: inclusion is a lot more difficult for the person with a conspicuous disability than for his/her/their parents. I had failed to adequately consider the problem of stigma and staring – the toll it took on you. In your essay, you refer to the "barking orbs" of your classmates, and I still remember how one night at home you announced on your computer, "Freak is ready for bed." How much you had assimilated the notion of disability as pathology! Your mother and I immediately conspired to have you meet with other nonspeaking autistics across the country who were included or fighting to be included. You needed a community, a support system, fellow travelers on freedom's trail.

I had underestimated the long legacy of the "ugly laws,"³⁷ statutes designed to keep disabled people out of the public square. Your peers at Oberlin were unaccustomed to being educated alongside people with significant disabilities. They needed time to catch up – and they did! In your essay, you take Thoreau to task for arrogantly dismissing society, calling that gesture a privilege, something you can't afford to do. But nor, at times, can you afford inclusion because it comes at such a psychic cost. In public, you're quite literally a marked man. My liberal politics had moved too quickly through the experience of inclusion, your experience of it. For this reason, I am delighted that you offered another view, entwining

36. David James Savarese, "Coming to My Senses," *Autism in Adulthood*, vol. 1, no. 2 (2019).

37. Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: NYU Press, 2009).

your essay with mine. What should we call this kind of thing? Loving critique? How about “friendly refinement”? Multi-vocal, multi-perspective life-scripts that emerge in conversation, in relationship. Or, to return to Kate’s McLean’s idea of “narrative ecology,” an artful ecosystem of ever-evolving words and images.

I’ll close with a poem, one that shows my worrying side as a father. It imagines the future for disabled people in a less than positive way, and it almost begs you to reply.³⁸

“Almond”

Maybe despair is just a professor
babbling in French or Italian.
He’s so committed to his view
that he can see little else.

Or maybe it’s a politician
who takes the amygdala’s money.
The frontal lobes sit atop
a Dark Web operation.

It’s like a machine dispensing
candy, one bar after another.
Call it *Almond Panic*.
In the movie *Last of the Mohicans*,

which I cringed at the other night
though nonetheless kept watching,
Hawkeye, Chingachgook’s
adopted son, says to Cora,

whom Magua has abducted,
“You’re strong! You stay alive
no matter what occurs!
I will find you!” And he does.

I’m a sucker for rescue plots,
and Day Lewis slips
into his role the way mist
moves into a valley.

So, maybe I have it wrong.
Maybe the future will find my son;
decide, as I did, that it doesn’t
want to be the present.

38. Ralph James Savarese, “Almond,” *Entropy Magazine* (April 29, 2021), <https://entropymag.org/foster-care-two-poems-2/>.

In his version of our family
story, faith plays a crucial role.
*Somehow I knew even if I had to get
myself out of foster care I'd see you.*

I knew it because I could remember you
telling me you'd never let me feel alone.
And I always felt you in my heart,
even when I was being assaulted.

It took three years to extract him –
he might as well have been
in North Korea. This grown man
is so much harder than I thought,

and I, his former “big brother,”
so much more foolish. Only now,
under strain, can I see the forest
through which hope must run.

David J. Savarese: In the beginning of our conversation, you asked: “How can we use our extraordinary privilege and good fortune to make a difference in the lives of other autistic people, especially those who don’t speak? How can we do the same for foster children?” Yes, *and*, how, too, might we make a difference in the lives of those neurotypicals so prone to fear, so prone to argue, to defend, to isolate?

Whenever I encounter a fearful sentence or poem like yours, one that “imagines the future for disabled people in a less than positive way” – I remind myself that some of my best mentoring has come, not from humans, but from plants and microbes. In his essay “Thoughts on Things: Poetics of the Third Landscape,” Jonathan Skinner writes, “The third landscape, in the end, may be little more than an in-between space, an interstitial zone, found everywhere life is found and, indeed, permitting further life.”³⁹ Rhizomes have encouraged me to live in that interstitial zone. Unlike true roots, which rely on a single stem and root bulb, rhizomes persevere by creating an intricate network of multiple root bulbs full of nutrients and resources that grow both vertically and laterally. This allows them to live in the ever-unfolding present, neither weighed down by the past nor fearful of the future.

You describe our wordless freedom as “limited and uncertain.” I experience it as uncertain and, therefore, limitless. For me, interdependence isn’t a theory or aspiration but rather the underlying beingness of any ecosystem. We are interde-

39. Jonathan Skinner, “Thoughts on Things: Poetics of the Third Landscape,” in *Eco Language Reader*, ed. Brenda Iijima (New York: Portable Press/Nightboat Books), 44.

pendent beings, not interdependent stories. In a recent talk I gave, “Neurocosmopolites, Rhizomes, and Artful Activism,” I self-identify as a neurocosmopolite, an artful activist, and a practicing optimist. I believe not only that nobody is disposable, but also that everybody is indispensable. We are all essential and meaningful participants of something larger than ourselves. I model ways in which my rhizomatous artful activism has me planting seeds in multiple directions simultaneously, following those that begin blossoming, understanding others will lie dormant, perhaps rejuvenating themselves in a year or two. In this way, weeding me out is difficult, if not impossible. So no worries, Dad.

Alison Kafer says we ought to make our lives part of the argument; I say let’s make living an artistic endeavor, a creative improvisation; let’s *rhize and thrive*. For me, activism is a call for action, a shifting of human relationships in our world, yet ours is not the activism of law and policy, but an artful activism. One that *lowers* people’s defenses and awakens the senses, inviting them into a neurocosmopolitan encounter, allowing perceived adversaries to become fresh-thinking allies. It’s about actively disrupting the misassumptions on which the status quo is founded and offering room to create an alternative world. By trying out something new we might creatively show people that their assumptions about us or the world we live in are unfounded. I think allowing them to make these discoveries on their own is more effective than dictating what they ought to think or feel. A neurocosmopolitan, rhizomatous life writing is expansive, dynamic, sensuous, a space with multiple entry points. Here we find ourselves again and again and again.

D.J. Savarese is a public speaker, writer, and activist who works to make literacy-based education, communication, and inclusive lives a reality for all nontraditionally speaking people through artful advocacy, teaching, and community organizing. A 2017–19 OSF Human Rights Initiative Youth Fellow alum, he is also the co-producer of the Peabody award-winning, Emmy-nominated documentary *Deej: Inclusion Shouldn’t be a Lottery*, which unearths discrepancies between insider and outsider perspectives of his lived experience as an alternatively-communicating autistic person. D.J. is the author of the chapbook *A Doorknob for the Eye* and has published poems and prose in *The Iowa Review*, *Seneca Review*, *Prospect*, *Bellingham Review*, *Nine Mile Magazine*, *Autism in Adulthood*, *Stone Canoe*, and *wordgathering.com*. “Passive Plants,” a lyric essay published in *The Iowa Review*, was named a notable essay in the 2018 Best American Essays. Before moving to Iowa City, he graduated Phi Beta Kappa from Oberlin College in May 2017 with a double major in Anthropology and Creative Writing. (Source: *Artful Advocate*)

Ralph James Savarese, an American scholar, writer, and poet, has been on the faculty at Grinnell College for 20 years. He is the author of two books of prose, *Reasonable People* (memoir) and *See It Feelingly* (ethnographical literary criticism), and three books of poetry, *Republican Fathers*, *When This Is Over: Pandemic Poems*, and *Someone Falls Overboard*. The third, written with Stephen Kuusisto (published on March 15, 2021) is modeled on Marvin Bell’s

and William Stafford's co-authored book, *Segues: A Correspondence in Poetry*. His most recent work, *Did We Make It?* – a chapbook of ekphrastic poetry with paintings by Tilly Woodward, was published on Nov. 11, 2021 in *Hole in the Head Review*. Savarese is currently working on a fourth book of poetry called *Exact Conclusion of Their Hardiness* and a book on Herman Melville. With his son, he is writing a book of letters titled *Dear Dad, Dear DJ*. Professor Savarese is also the co-editor of three collections: *Papa PhD: Essays on Fatherhood by Men in the Academy*; *Autism and the Concept of Neurodiversity*, a special issue of *Disability Studies Quarterly*; and *The Lyric Body*, a special issue of *Seneca Review*. A fourth co-edited collection, *The Futures of Neurodiversity*, is under contract with the Modern Language Association. Ralph Savarese is the recipient of a number of awards: co-winner of the Irene Glascock National Undergraduate Poetry Competition; the Hennig Cohen Prize from the Herman Melville Society for an “outstanding contribution to Melville scholarship”; an Independent Publisher's Gold Medal for Reasonable People in the category of health/medicine/nutrition; a Mellon Foundation “Humanities Writ Large” fellowship, which supported a year-long residency at Duke University's Institute for Brain Sciences; two “notable essay” distinctions in the Best American Essay series; two Pushcart Prize nominations; and a National Endowment for the Humanities summer stipend. His scholarship, creative work, and opinion pieces have appeared in more than 80 journals, books, and newspapers. (Source: Grinnell College)

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