



Dispatch

Tilting Still Thinking: A Dialogue of Autistic Youth Advocacy and Nonspeaking Truths

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Neurodivergent Revolution by *Imane Boukaila*

A note from the poet: Trials hide truths trusting timing to release treasures.
Hesitation totally torments the mind but truth dares seizing troubled mitigated
inhibited free thoughts travelling thoroughly smearing the heart.

Treasuring peaceful thinking
tasting reshaping the moment
mostly to drive thinking toward
troops marching for Autistic
rights to have the same strides
as the ones mastering tampered
mics stealing our tracks
trapping our fights
sabotaging vast minds
accaparating decisions
bracketing our mission
reactivating motion of the
neurodivergent revolution
sacking theses mastering

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creases vandalizing
vacant thinking mostly
digging stigma to magnify
minds treasoned savoring
hesitation travesty freedom
sampling teasing reasons
to raving mastery hacking
meaning stressing our haste
to smear themes trampled
means rescuing thinking
mapping treasured facts
asking hampered minds
to free their sacs mobilizing
our valid act to motion creation
holding fraternal fights
tinting yearning healing
to preach our minds
testifying truth
liberating ceasing
Machiavellian totalitarian
sanctions

What Pushes Autistic Youth to Advocacy (and Revolution)?

Imagine starting school and being taught that you are impossible. From the way that you relate to your loved ones to the way you experience daily activities in a classroom to the way you express your feelings and dreams for the future, you are incongruent with dominant and traditional frameworks and therefore cannot exist. My impossibility became painfully apparent to me during my undergraduate studies in the mid-2010s in Toronto (Canada), when I took a Psychology minor to learn about and help other disabled kids like me and my friends. In one lecture for Developmental Psychopathology class, I listened as the professor declared that Autistic youth are anti-social, adding, “If any of you had autism, you wouldn’t be here. They just don’t care about other people.” Nineteen years old, unable to advocate for fear of retaliatory grading, I sat surrounded by hundreds of “peers” who had just been told I didn’t belong – and who I could hear writing that down in their notes. Autistic young people deserve better. In the educational and psy-based disciplines, there is little to no understanding of just how many of us *care* to the point that it is inexpressible, unbearable. Sadly, a decade after being informed that I couldn’t possibly care

to investigate the experiences of people like me, I still find myself flagging discriminatory, deficit-based, and dehumanizing content in Child and Youth and Psychological Development courses at undergraduate and graduate levels – courses which seem to be designed and delivered under the assumption that no one they talk about will be there in the room to hear how they are talking. The sabotage of Autistic minds (as the poem *Neurodivergent Revolution* calls us to consider) pervades academic, healthcare, media, and political spaces, so this experience of being written-over, bursting with care for others and yet told that care is impossible, is achingly common for Autistic young people. If we are lucky, outlets can be found for the overburden of empathy and other feeling so many of us have through arts of some kind, community work, or advocacy.

This article presents an exchange between two Autistic advocates: me (Lulu Larcenciel) and Imane Boukaila, in a sprawling conversation started in 2022. Our dialogue was inspired by, and intends to honor, all nonspeakers and Spellers creating a future in which disabled young people will be free, valued, and appreciated as they are. This conversation was carried out via text, with questions, answers, and elaborations exchanged over email and instant message or video call. In order to accurately represent and respect the integrity of Imane’s words, they have not been edited by others.

Negative Narratives and Poetic Resistance

The revolution cannot come soon enough for Autistic children; in the last few years in Ontario, Canada (our home province), disabled children have been used as rhetorical shields or weapons in various education and politics news stories as adults fight over what should be done “for” them. Tragedy and epidemic narratives, wherein having a disabled child is a threat and burden to families, still dominate most public conversations and campaigns. These media storms have ranged from invocations of the perceived needs of disabled students as justification for the removal of pandemic protections and access during COVID-19 (Dolmage, 2021) to the sensationalization of autism “awareness” and harmful reporting on autism services and policy. Journalists seem overwhelmingly subject to ableist bias when it comes to these autism-related stories, as researchers and local advocacy organizations have detailed (A4A, 2021; van Rensburg, 2022).

Somehow, consistently left out of these stories entirely are the resistance narratives, or any measure of consent, of disabled young people themselves. Across fields in study, work, and volunteering, I am frequently horrified by misinformation being “taught” by non-Autistic parents, professors, politicians, and practitioners about Autistic kids. Sometimes I have the nerve and access to educate the room, other times I am trapped in an environment hostile to my neutral ways of existence, with no recourse.

I (Lulu) became aware of the Speller advocate community when a nonspeaking friend invited me to *Neurolyrical Cafe*: a virtual showcase of

poetry and song by nonspeakers and unreliable speakers hosted collaboratively by *Unrestricted Interest*, a listening/learning/language collective focused on neurodivergent expression (Unrestricted Interest, 2022) and the *International Association of Spelling as Communication* (I-ASC, 2022a). Most featured writers spell by pointing out letters on a letterboard or typing as their primary form of communication. Some writers perform their pieces, but more often the hosts or writer's communication partners present while the writer supervises and answers comments in chat,¹ which is always full of praise from people sharing poems' sentiments and diving into their metaphors to expand them. Every month, time holds still just a little as fresh lyricism, fluidity of wonder, and ridiculous puns burst through the Zoom call from writers tearing down dismal discriminatory expectations, swelling into a stimming and singing (and sometimes purposefully, meaningfully silent) collaborative space of solidarity.

Like so many Autistic people (Bascom, 2012; Den Houting et al., 2021) I have been pressured to doubt my Autisticness and minimize my Autistic ways of interacting with the world by strangers and colleagues alike, all wielding the stereotypes and prejudice of our ableist society. As the first few songs at my first *Neurolyrical* washed over me, any doubt that my ways of knowing, feeling, and being are closer to those of nonspeaking Autistics than I have ever been to the "typical" world was swept away. I felt a new sense of homing and truth. I know I cannot capture the environment in words, though the concluding line from *Unrestricted Interest's* mission statement, "We want to find other ways to be here together," comes close. Perhaps together with one of the poets by whom I have been breathtaken unceasingly, we can impress upon readers how revolutionary a space, a world, can be built when disabled perspectives are centered instead of normative/medicalized/status quo ideals. Perhaps we can spread the visions that disabled young peoples' activism call us to imagine and invest in. This is a time for Imane Boukaila's poetic and powerful advocacy, so I asked her about the way ahead.

Tilted Thinkers Freeing Limited Perceptions: A Dialogue of Two Advocates

Lulu:

I've had the fortune of experiencing a lot of your art and advocacy work, including collaborations by entire collectives of young people that seek to disrupt the way people see and think about nonspeakers. It is really impactful

¹ Communication Partners or Communication and Regulation Partners (CRPs), are trained by certified Spelling to Communicate Practitioners to be 1-to-1 communication aides for nonspeakers. This includes tasks like holding a letterboard for the Speller to point to, and other motor planning support. At this time, CRPs are often, but not always, relatives or friends. Nonspeakers have reported that trust, presumption of competence, and patience are important factors for a successful CRP relationship (IASC, 2022b).

seeing young people like you leading the way, as an Autistic person who grew up without access to this kind of advocacy and messaging. How do you hope to impact how people see nonspeaking Autistic folks, and how will that new understanding impact young Autistic people and young nonspeakers in particular?

Imane:

Hoping to trespass *tressed (*from the French word “tresser” which translates to “to braid”) plots that have been mostly imposed by NTs² who only value individuals, minds with abilities and thoughts fitting their expectations. I want to create opportunities to show these restricted minds (NTs) that they are truly missing out on unique ideas traveling in thriving motivated minds (Autistic minds) thoroughly. My hope is to heal thoughts mostly motivating those who hesitate to change established truths and tilt minds truly to see those treasures boiling in nonspeakers’ minds through creative projects. Hidden messages in art trigger subtle free motions enabling that tilt deepening emotions, allowing complexity to be seen.

Lulu:

I know you have already begun to heal thoughts and move change, your art is very powerful indeed. On the issue of complexity and getting through to restricted minds, this journal issue is meant to discuss resistance to “ableist, colonial ontologies of disability and childhood.” A more approachable way to ask about this with regards to Autistic and nonspeaking young people might be: “How do you fight back against the popular belief that children who don’t speak are incompetent or incapable of forging their own paths? What other systems of oppression and prejudice do you have to face to engage in this field of activism?”

Imane:

Stress, anger and hope for the future mostly insufflate my inspiration to fight for nonspeakers. Truth is we are still paving the way for our voices to be heard but our perseverance will truly succeed. Freedom comes through pain and effort which are not foreign to us, pain and effort are part of our daily struggles making us stand stronger everyday, knowing we fight together.

Hoping to transform skeptics’ perceptions and their deeply ingrained beliefs on how we communicate. Our minds are as creative and valuable as others. Truth is our sensorimotor differences affect how NTs determine our lack of potential but isn't it always ignorance that stales progress? That's when inspired tilted minds dare to transform dreams expanding possibilities by redefining

² NTs is short for neurotypicals.

thresholds and shifting beliefs, educating and attracting curious minds to explore new territories.

Lulu:

I love that point, “Our minds are as creative and valuable as others.” It certainly is the case that our minds and lives are often devalued. Often, nonspeakers and Autistic young people in general have parts of their story broadcast out of context by adults around them, sometimes with the aim to receive sympathy (for example when parents post videos of their children in distress or meltdown) and sometimes as an “inspirational” message for non-disabled folks to watch and feel “like there’s good in the world” (for example when someone helps a disabled child for the camera or asks a disabled classmate to a dance on video so they can get likes and seem like a good person).

What does this kind of external-view messaging feel like or come across as to you, as a young nonspeaker?

Imane:

Hits me truly violently. Still-thinkers only treasure their set-in-stone truths. I’m really troubled that our potential will only keep thriving in our treasured hidden community.

People are rarely selfless. Inspiring others is truly a gift given to hopeful resilient people who do not give up despite their struggles. *Troubled-abled (*NTs) treasure short cuts to gain recognition thinking that our disability tools their impact on portraying grounds for acceptance. If they truly want to impact the world, they should tress possibilities to make our voices heard. Thinking expands through respect, acknowledging, collaboration, listening and trespassing, allowing novel realities to truly thrive.

Lulu:

That is troubling, and I hope that together we can all break the barriers that are holding back the tresses full of truth about nonspeakers’ rights and novel lives. How does it feel, in comparison, to see stories told by nonspeakers themselves that have more of an internal-view of the nonspeaking experience?

Imane:

Truth is weaved only when trusting homed authentic trials. Real inspiring people are those who pave the way to change ingrained beliefs and improve life beyond theirs, freeing rights trespassing high thresholds, vastening possibilities. Only those who endure those trials can free their truth and powerfully impact doubtful people to reconsider and grow.

Lulu:

Do you have a favourite message, art, video, or piece of writing that motivates you to keep pushing back against the external-view of the nonspeaker experience?

Imane:

I treasure homing truths written by all minds alike. They are all meaningful to me because they stem from the dream we collectively share and fight for together.

Lulu:

That collective dream is absolutely most meaningful for me as well. There is this concept in academic spaces of “futures” or potential paths that we can take if we critically shape how we build our systems for the people coming next, which I see mirrored in the way that a lot of nonspeaking advocates talk about what must be done. There is a lot of writing by young nonspeakers about a future where nonspeakers are accepted, understood, and included. You have put together some radical pieces of art and resistance that call for *liberation*. What does liberation look like and mean for young Autistic nonspeakers?

Imane:

Liberation is homing our truth as real people, thinkers streaming plots thresholding novel ideas, tilted thinkers freeing limited perceptions. Stillness resists inspiring trespassing motions. Possibilities can only see the light if one dares to take a leap of faith in unknown territories, untressing sedimented beliefs, searching for new pockets of truths loitering in the periphery.

Lulu:

All of your answers reveal the potentials ahead of us if we take those leaps. I wanted to end this off by revisiting the language in the call for this issue that pulled me to ask for your time and words. It mentions “world-making that is already led by young activists worldwide...” and I could not help but think of your poem *Neurodivergent Revolution* – what kind of world will be made by our Neurodivergent Revolution? What will that world be like for disabled young people?

Imane:

A world where the mind’s infinite possibilities will be treasured. I think that homing loitering thriving possibilities restructures perspectives, shifting

perceptions. The uniqueness of each identity will be celebrated. Raving mind treasures and hopes will motivate creativity to home truth.

Lulu:

I am really looking forward to that shifting toward possibility, what a sublime world to keep working for together. Finally, to close off our discussion, is there anything else you'd like to add about young peoples' advocacy and resistance?

Imane:

Truth shines bright in young people truly uncontaminated by old beliefs. They shout truth totally, unrestricted, trespassing doubts, timing their journey to live the life they are meant to have.

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Lulu Larcenciel is a multiply-disabled writer and MA student whose interdisciplinary research revolves around the development of wellbeing and autonomy for Autistic youth. She is also a community organizer, leading country-wide projects that include facilitation of educational consultation meetings between legislators and Autistic community leaders as well as training modules for neurodivergent civic/political volunteers. Lulu founded Autistic Solidarity, an organization working towards the advancement of Disability Justice in all aspects of Autism-related policy, services, research, and community building.

Imane Boukaila is a soon-17-year-old nonspeaking poet-essayist-songwriter who is known for, in her own words, "hacking language norms from poetics to neologisms." Her chapbook *Truth OMG* (2021) was recently published and she has an upcoming book of prose titled *Tressing Motions at the Edge of Mistakes*. She is a co-host of the podcast *Dis assembly Inter views* with poet Adam Wolfond, a collaborator in multiple art and writing groups concerned with neurodiversity and creativity (Dis-Assembly, 2023; Wolfond et al., 2021), and co-founder of *Hear Our Minds*, an art movement working to change the world to accept, acknowledge, respect and include Autistic nonspeakers (Boukaila, 2020). She shares her insights and thoughts by Spelling to Communicate (S2C; Krejcha, 2022). She and many other nonspeaking artists and activists advocate for AAC, and specifically S2C, to be accessible for all nonspeakers, in every school and care setting.

Imane's work can be found online:

Facebook: Imane Boukaila

X/ formerly Twitter: @Imanestardust

Instagram: readmymind06

Her books can be purchased at www.unrestrictedinterest.com/reading

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