

Silenced Voices: Situating Disability Studies in France through the poet Babouillec

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Context.

Disability studies is a growing field of research in the US, but has been slow to take root in countries with more conservative academic structures like France.

Representation of the experience of life with a disability is challenged when individuals face barriers of communication or stigma about their abilities.



This thesis.



This paper looks specifically at works by and about Babouillec, a young French poet with autism **classified by her doctors as “deficient by 80%”**.



I evaluate the **ways in which the mediation of her story** by those around her (in the production of her story for publication, cinema, and theater), as well as my own critical position in narrating her story, **influence the ways in which these works are received**.



How do we decide who is qualified to tell someone else's story? More importantly, **what kinds of mediated stories of disability are we receptive to?**

Disability Studies.



Disability vs. “handicap”

Terminology: etymology and stigma behind the word handicap.



Disability studies in France

Disability studies is a new field in France due to academic traditions that have been resistant to interdisciplinarity.



Autism: models & treatments

France uses a medical model as opposed to a more social model in the US. My interest stems from being a behavioral clinician for children with ASD in the US, where treatment is focused on integration of children with special needs. In France, individuals with autism often live in institutions.



Narratives by individuals with autism

Those with autism often describe their experience as separated from the rest of the world by doors and glass.

Babouillec.

Hélène

Poet with autism who writes under the name Babouillec.

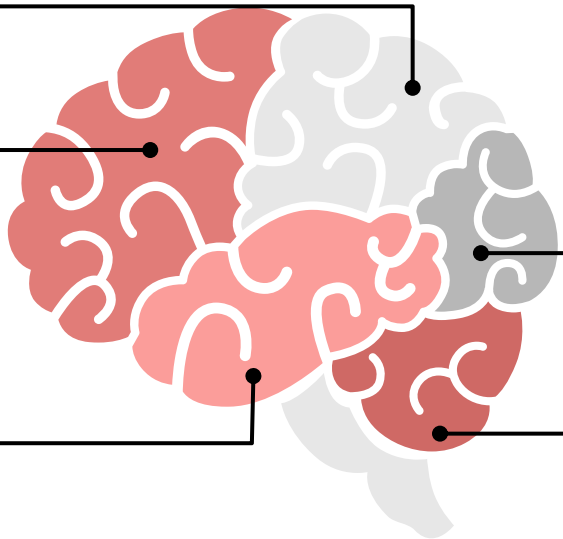
She was never officially schooled, and learned to write at 20 years old by arranging laminated letters.

At 30, she wrote *Algorithme éponyme* (2013) about her experiences in the world.

Poetry

Babouillec expresses profound emotions through her writing.

Often, she address themes of being misunderstood, as well as evoking the simple joys of life that neurotypical individuals often take for granted.



***Babouillec's poetic imagery:
brain & mechanics.***



Neurons



Biology



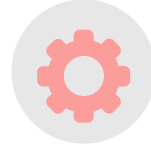
Connections



Wires



Sparks



Codes



***“Is thinking in silence a reasonable act?
I spent long years
cut off from the world of speech.
It was impossible for me to engage in
the established codes. Mutism took hold of my body, my
mental intelligence is enclosed
in this silent body.
I adore words, the potential extension
of thought without limits.
So I wrote; an act of believing.
Giving to your reasons a meaning to my silence.
Each of my mental images invites me to visit
the order of thought materializing our world of
established knowledge. What an uncertain, exalting,
puzzling adventure”
–Babouillec.***

Mediation of Babouillec's Narrative.



- Film, *Latest News from the Cosmos* (2016) by Julie Bertuccelli
- Performance art, *Forbidden di sporgersi* (2015) by Pierre Meunier
- This thesis itself



- As a mediator of her experience, the goal is to **celebrate Babouillec's humanity** and her diversity of thought.
- However, as a nonverbal person with autism, Hélène, and her story, are **particularly vulnerable to misinterpretation.**

Conclusions.

I hope that with **conscious mediation of the work of authors and artists with disabilities**, we will be able to broaden the public's interest and investment in the works of these people.

These **works themselves are gifts for their audience**, and we are deprived of this experience when we overlook them for being unrelatable.

I am aware of my limits, but this thesis is a step towards **mobilizing these silenced voices** sharing their experience of disability.

- By repressing the art of people with disabilities out of disinterest, we send the message that we don't care enough about these people to open the door that separates us and learn about their experiences.
- The stories of individuals with disabilities are valuable for their contribution to our understanding of the human experience, not just as examples of alternative experiences.

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