Web cartography : what are the possibilities for neurodiversity and digital activism ?

Lucas Fritz, Phd candidate in communication sciences (DicenIdf / Nanterre) and sociology (IRIS / EHESS).

Visuals are followed by the script of the presentation (p. 40 to 50)

Structure

- 1. Short introduction about my PhD project
- 2. Tools and analytical frame to study what is happening online
- 3. 3 main results on neurodiversity and digital activism in France
- 4. Possible adaptations of the Web cartography for further explorations
- 5. Possible adaptations of the Web cartography for digital activism

As I described in the dedicated section in Autscape's website my presentation will be divided in 5 equal parts, each part will take 5 minutes maximum.

- first of all I will talk a bit about general aspects of what I am working on, my problematics and the directions I am looking at to answer those questions (1)

- then I will talk a bit more about digital activity and activism and the methodology I am using: digital ethnography and cartography of the web. I will linger on the technical aspect of the methods I am using, especially the software but also the analytical grid I use.

The idea is to shed light on the results and put them into perspectives but also to show you the most of it so you can reproduce it at home with friends, allies or for your own pleasure (2)

- Then I will present some of the results on a cartography of the web I did of 500 websites around autism and neurodiversity in France and I will focus on the general aspects of the map, the place of parents of autistic people and institutions in the map, the place of associations of autistic people, and the places of the blogs. I will use this map to talk a bit more about the situation of neurodiversity in France, the current political and scientific tensions online, the future possibilities for neurodivergent digital activism. (3) (talk a bit more about scientific and political tensions in the digital sphere in France)

- Then I will take a critical distance from my results and try to explore with you several directions to ask better questions from this cartography (4)

- (5) and also explore possibilities given by the cartography to direct a project of digital activism or to carefully choose what to publish online. During my PhD thesis I met several actors (associations, activists, but also parents, institutions etc.) whose websites or blogs are on the cartography, and they appropriate themselves the map in different manners.

1.0 Introduction

- Phd candidate
- 3rd year
- Member of CLE-Autistes (self-advocacy association of autistics)

I am a PhD student in sociology and communication sciences in my 3rd year in University Paris Nanterre and EHESS, and I am also a member of CLE-Autistes, a collective that fights for the recognition of autistics' rights and the recognition of the neurodiversity paradigm in France.

In France PhD thesis in social sciences lasts usually between 4 years and a half and 5 years. Being in my 3rd means I am done with observations, interviews, and presence with the actors, and I am now writing the thesis itself. As I am still processing some observations, I will not be able to talk about every aspect of my work

So to talk a bit more about the general aspect of the thesis : I am working on the emergence of the concept of neurodiversity and the reception of neurodiversity movements in the public sphere in France - I am working on it from a double point of view: the one of sociology and the one of communication sciences.

1. 1 Introduction

- Web = hospitality
- Web = a place where people can gather
- Web = a tool to overcome difficulties people face in everyday situations

So as you might know, in her book Neuroqueer heresies published in 2022 Nick Walker defines "neurodiversity" by the diversity of human brains, the « neurodiversity paradigm » by the fact that all brain are different and that there is no such thing as biologically normal brain (any norms of neurological functioning are based on cultural expectancies) the "neurodiversity movements" are the political and intellectual movements lead by people who identify as neurodivergent or neuroatypical and wants other to recognize that their neurological difference is cultural.

To organize themselves, those movements primarily use certain digital devices such as forum or social media, especially for their material characteristics of asynchronic communication, people have time to write and answer, rules of communication are clearer than face to face interaction etc

1. 1 Introduction

Odd People In: The Birth of Community amongst people on the Autistic Spectrum. A personal exploration based on neurological diversity

Judy Singer

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Social Constructionism/ Constructivism, Neurodiversity, Social Housing, Disability Rights, Public Housing ...more -

The thesis was the first social-constructionist account to map out the global emergence of a new category of disability, the new "neurological disorders". The work was part autobiography, part social research as a participant-observer in an online community of autistics, part advocacy for a new way of seeing formerly "odd" people now rebadged as "disabled". The thesis framework built on the British based "Social Model of Disability", which augmented by the work of American disability thinkers, especially that of Deaf theorist Lennard Davis. A thesis presented to the faculty of Humanities and Social Sciences in partial fulfilment of the requirements for the degree of Bachelor of Arts Social Science (Honours), Faculty of Humanities and Social Science, University of Technology, Sydney, 1998. Approximately 17,000 words.

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ABOUT AUTHOR



Judy Singer developed the portmanteau noun Neurodiversity as a banner term in call for a Neurodiversity Movement. Identifying as being "in the middle of three generations of women 'somewhere on the autistic spectrum', her work was based on participan ... more -

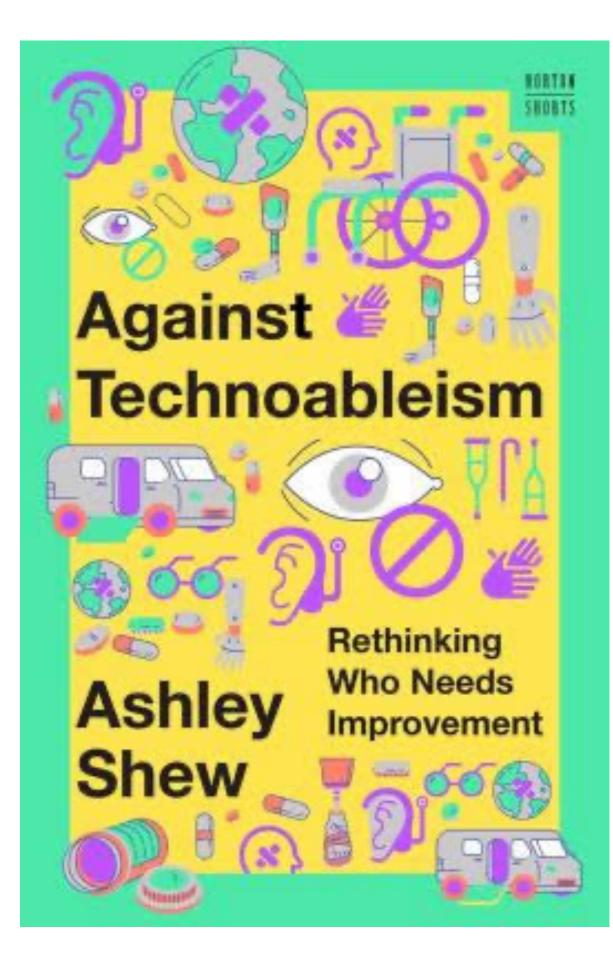
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Uncovering the Neurological Procrustean Bed: Judy Singer	
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POPULAR RESEARCH INTERESTS	
Medicine 5962243 followers	+ Follow

Also multiple works (Judy Singer, Blumes), testimonies (Rey Meyerding, Jim Sinclair), showed, internet was emancipatory for neurodivergent people.

1. 1 Introduction : inhospitality

- Web = dynamics of power (Badouard 2022)
- Web = friction of accessibility (Fritsch et Hamraie 2019)
- Web = a dismediatic tool baring a certain image of the body (Sterne et Mills 2017)

1. 1 Introduction : inhospitality



1.2 Introduction : problematics

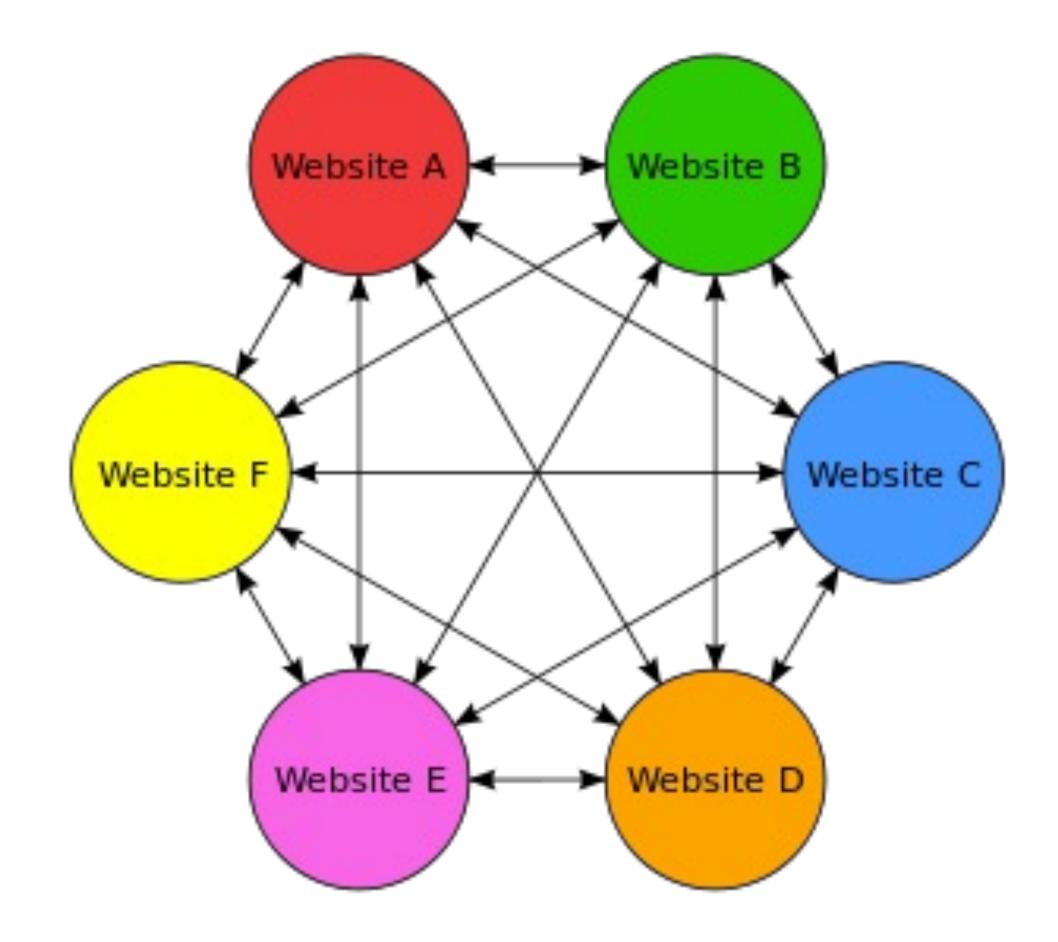
- neurodivergent discourse?
- autistic, neuronormal user?

 what is the place of communication devices and especially digital devices in the emergence of neurodiversity movements and the recognition of the

How autistics appropriate a digital environment that was designed to a non-

1. 3 First field : digital field

- 505 websites
- Web mapping
- Ethnographic study of their connexions online and offline for 12 websites.
- Interviews.



1. 3 Second field : digital field



Collectif pour la Liberté d'Expression des Autistes



希 -> Qui sommes nous -> discord



1. 3 Third field : medical field

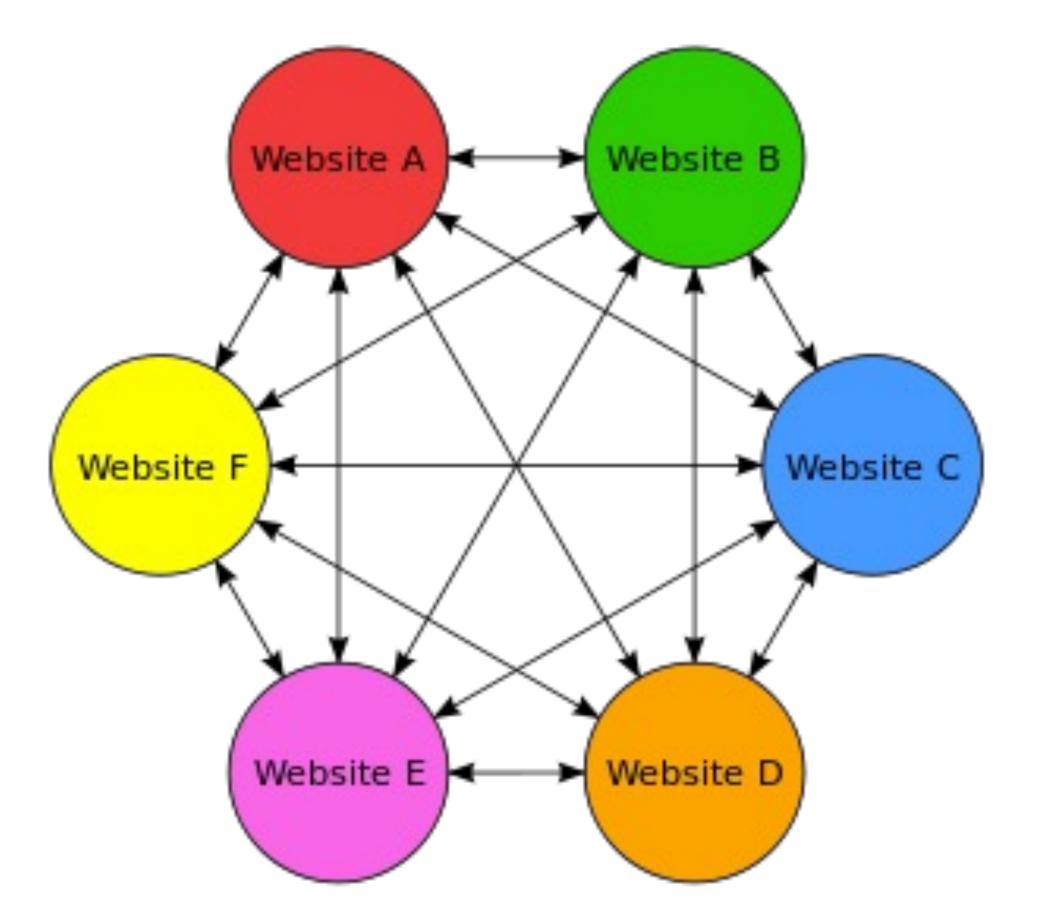


2.1 What is the web?

hypertext system operating on the Internet that allows users to consult pages accessible on other sites using a browser. The image of a spider's web comes from the hyperlinks that link web pages together." (Wikipédia France).



2.1 Visualizing the web



2.1 What is the web?

embodied by fixed html pages (Rogers 2015)



Hyperlinks (the insertion in a website of a link leading to another website) can be seen as traces of social interactions from one actor to another - actors here



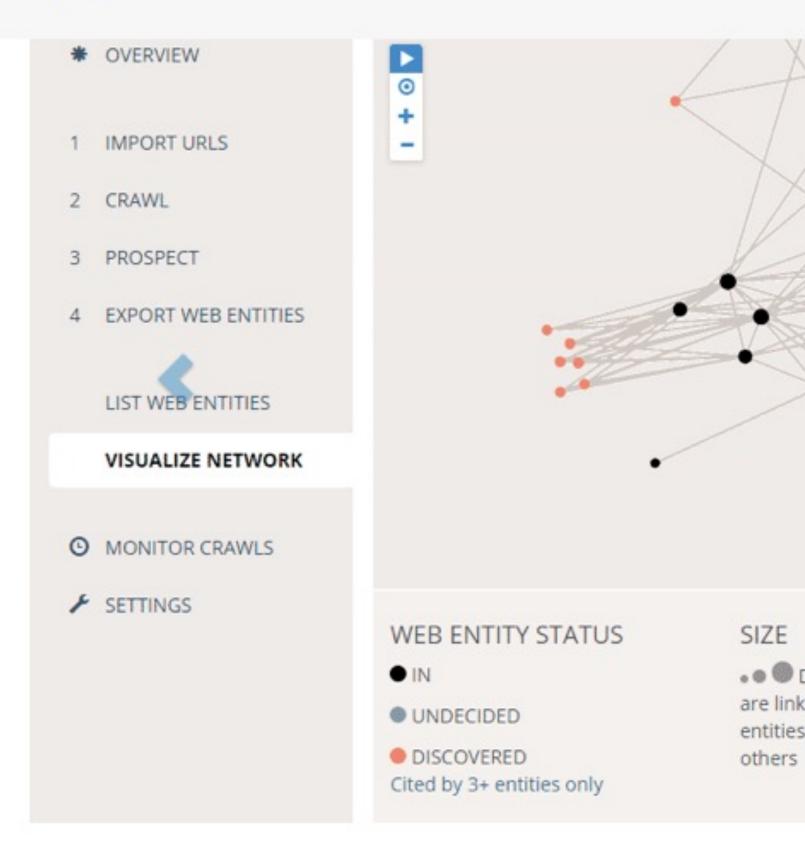
2.1 Methodoloy to analyse the field : (n)ethnography

often have to take place in person" (Kozinets 2015, p 13).

 "Netnography is a special case of online ethnography. It requires participation through commitment on the part of the researcher and interviews that most

2.2 Tools to build the field : Hyphe

Hyphe

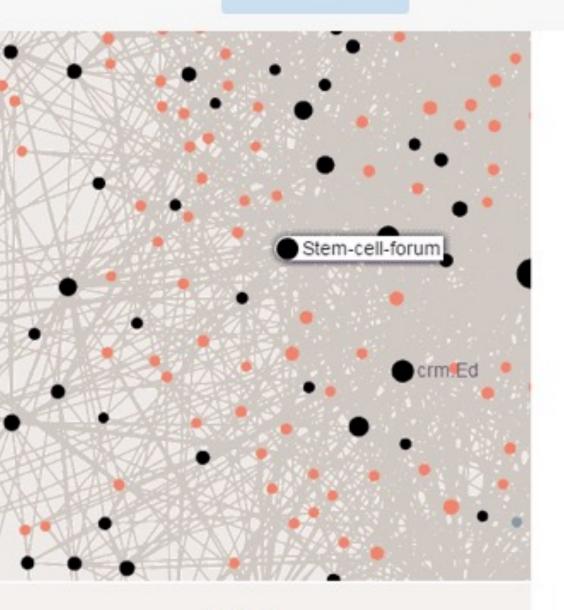


INTERFACE

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HOW IT WORKS

UNDER THE HOOD



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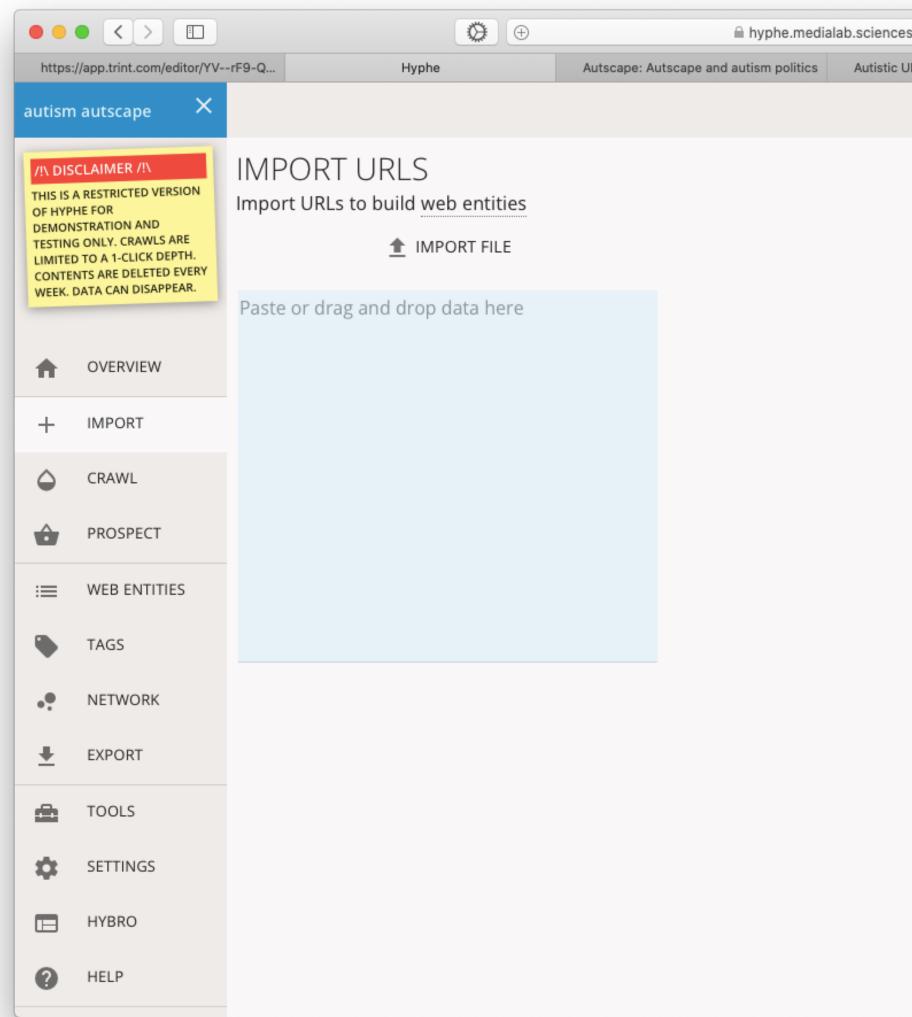
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DEGREE: Small web entities
 are linked to few others, big
 entities are linked with many

------ Hypertext link between entities

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2.2 Hyphe step 1 : importing



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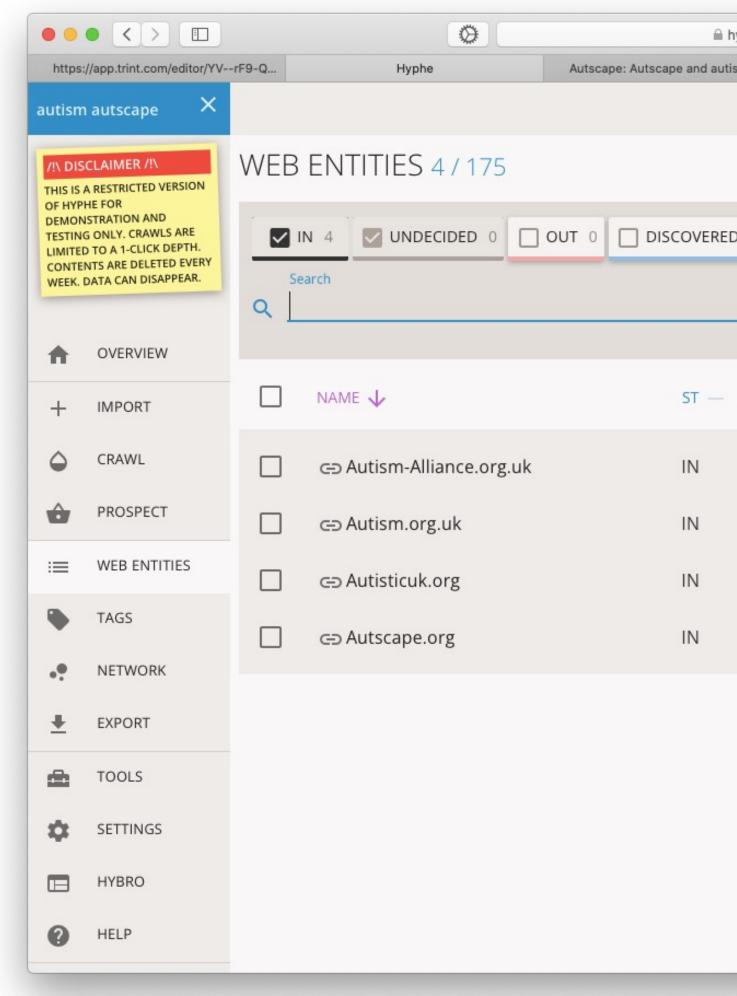
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2.2 Hyphe step 2 : crawling and waiting

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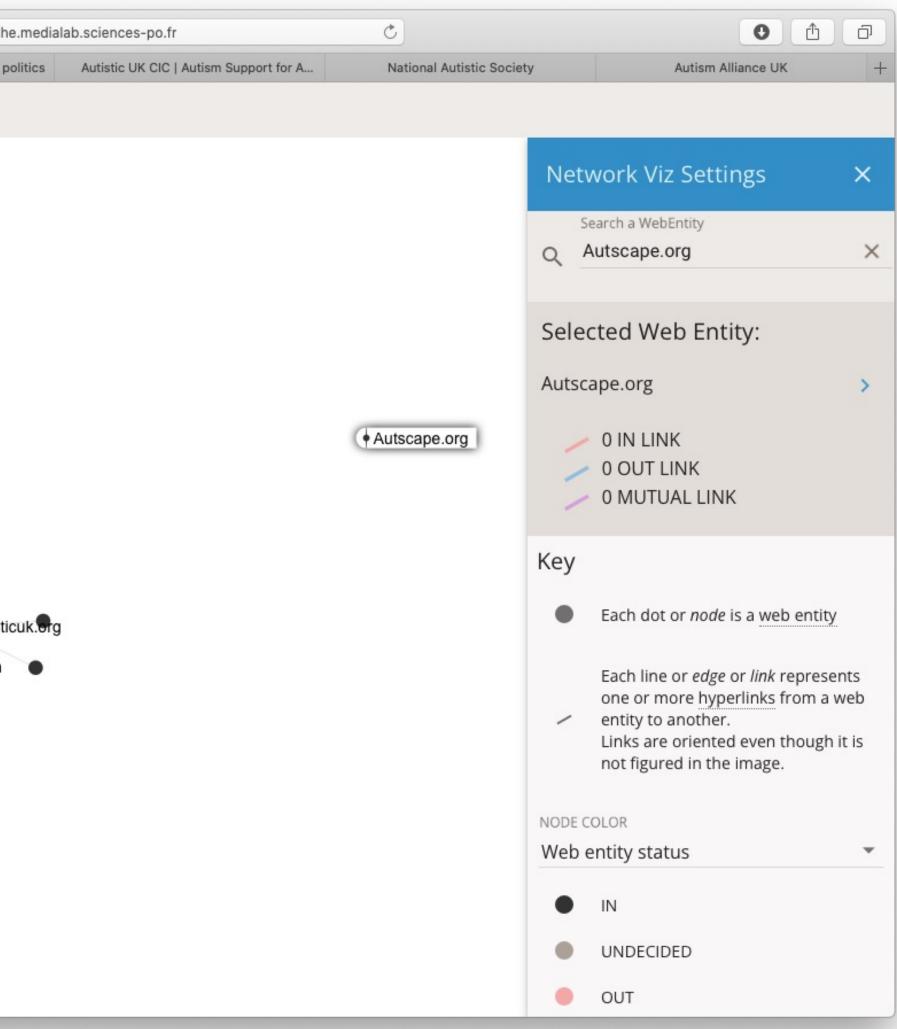
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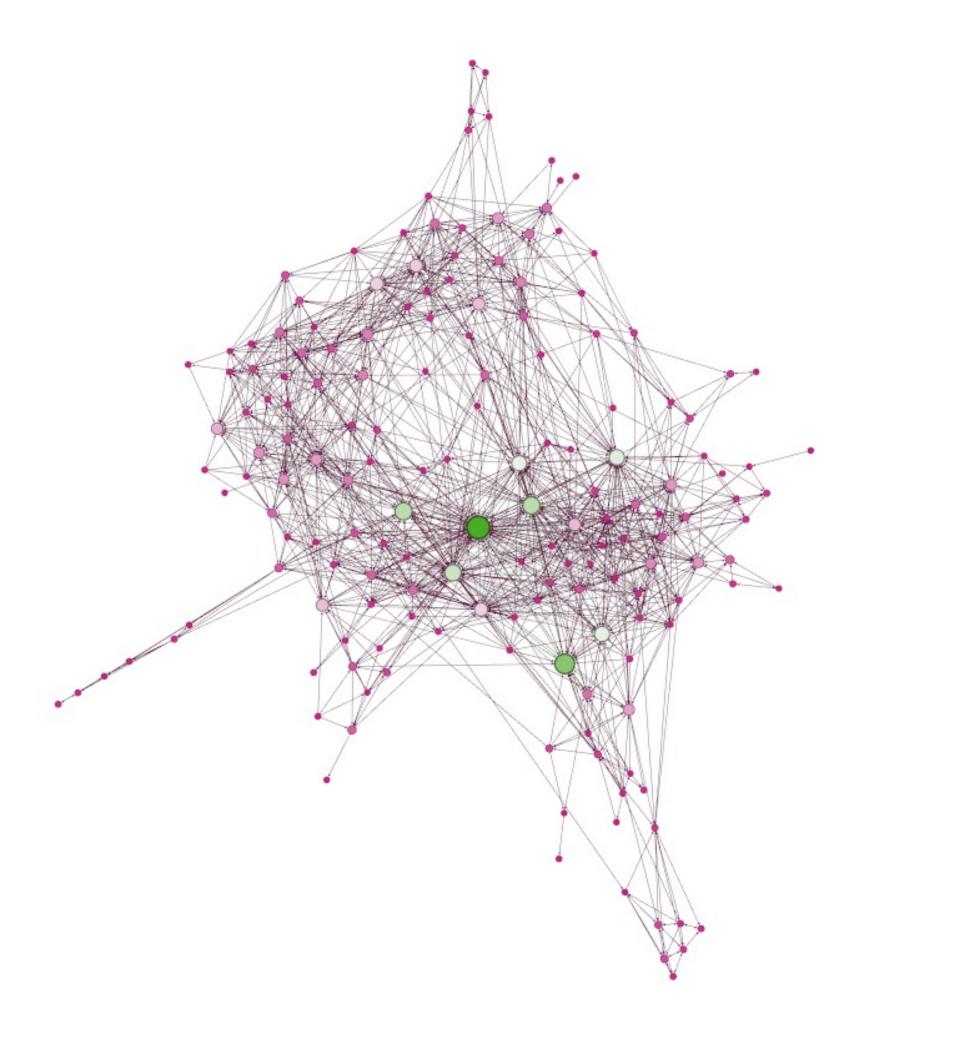
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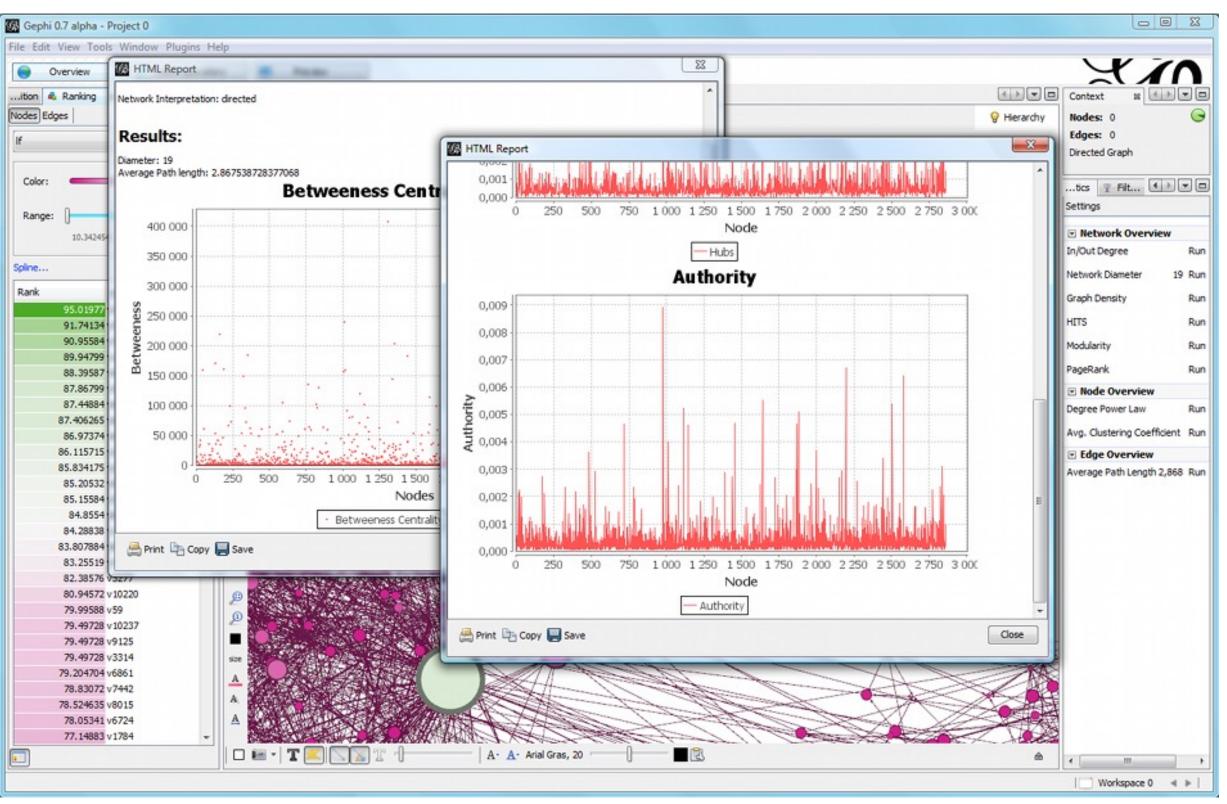
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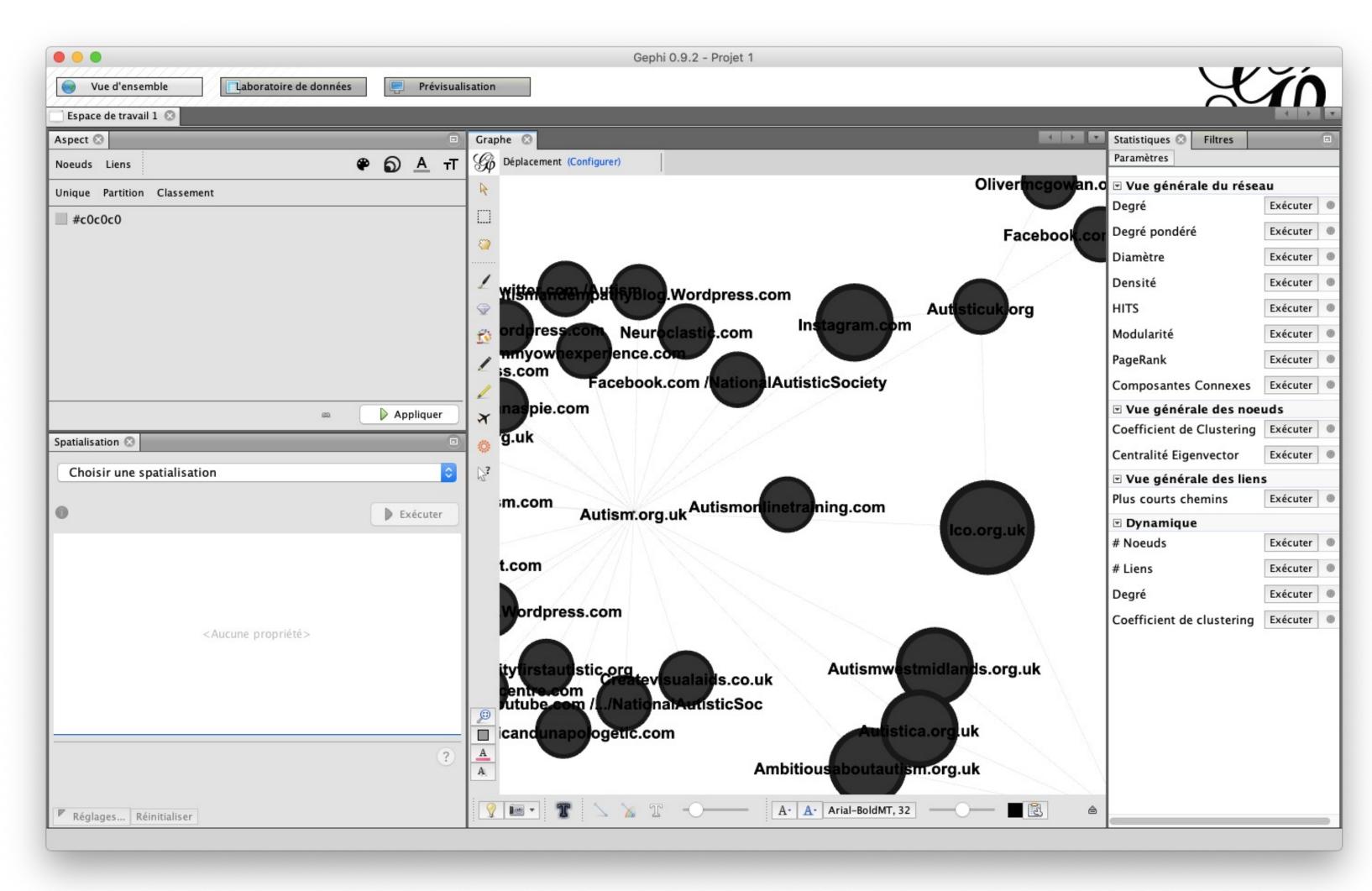


2. 2 Exportation to Gephi





2. 2 Exportation to Gephi



3. Building the field

- health, publics dispositives etc)
- I ended up with 505 websites.

100 websites on "neurodiversité" + 25 institutional websites (HAS, Ministry of

3.1 Building the field

Labelling :

- Posture toward it : non, neutral, against, in favor
- Nature of actors : association of parents, association of autistics, public health, professional insertion, formation of autistics.
- Location : France, Europe outside France, America (United States and Canada), Multiple locations (transnational projects for example).

• Mention of "neurodiversity" : non, few, often, very often, the site is about it.

dispositive, blogs of autistics, other type of blogs, media, professionals of

3.1 A very strong lobbying of parents and a tiny resistance from public actors.

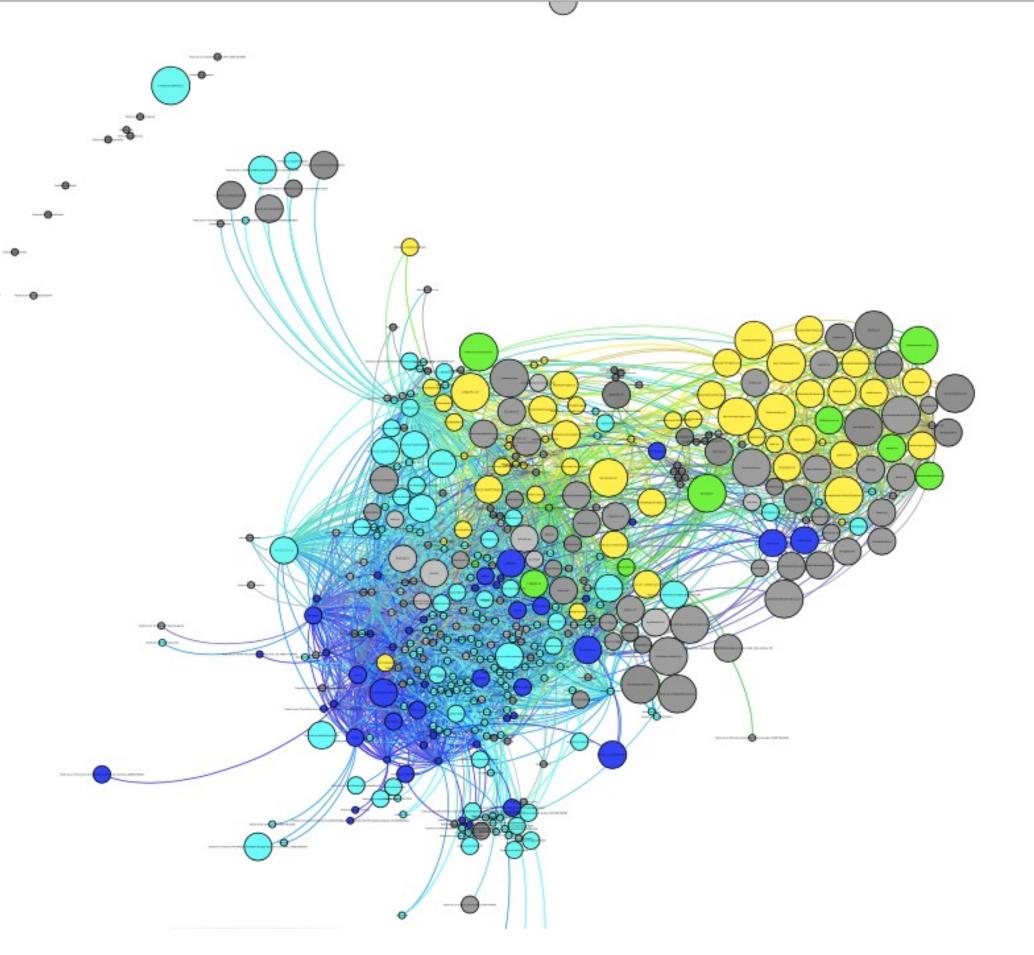
- Size
 - indegree
- Color
 - Pale blue = association of parents
 - Dark blue = public institutions
 - Green = association of autistics
 - Yellow = blogs

3.1 A very strong lobbying of parents and a tiny resistance from public actors.

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3.2 The concept of neurodiversity recaptured by association of parents in an international context.

- Size
 - Mention of neurodiversity
- Color
 - Pale blue = association of parents
 - Dark blue = public institutions
 - Green = association of autistics
 - Yellow = blogs



3.2 The concept of neurodiversity recaptured by association of parents in an international context.

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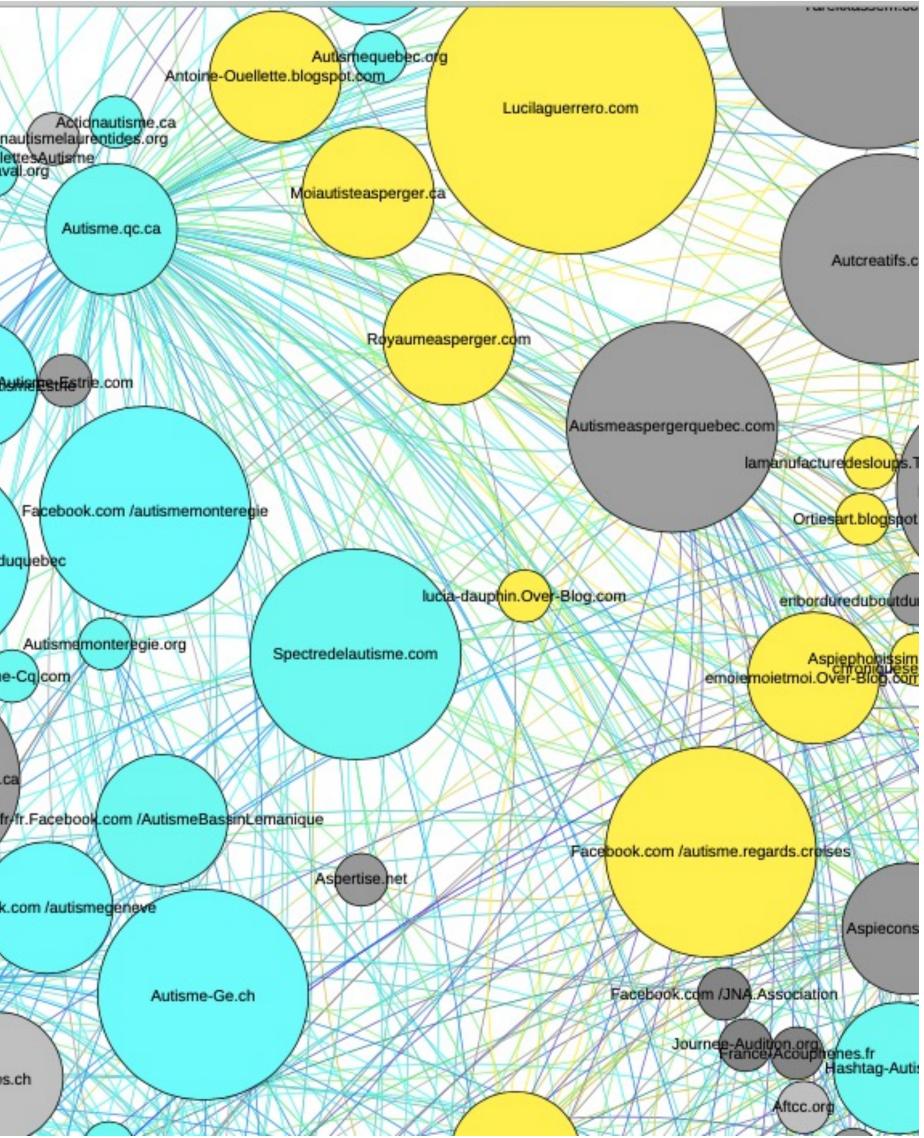
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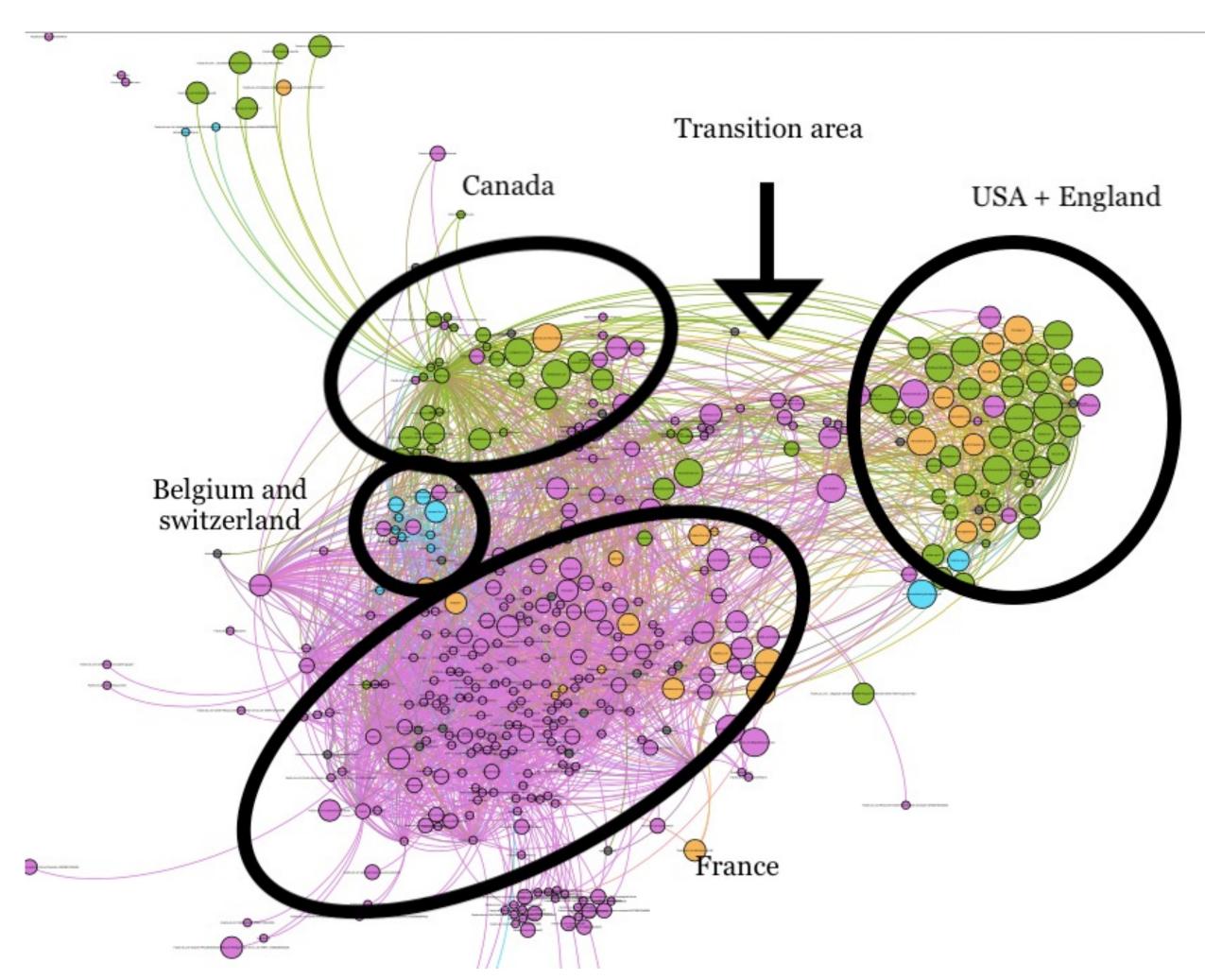
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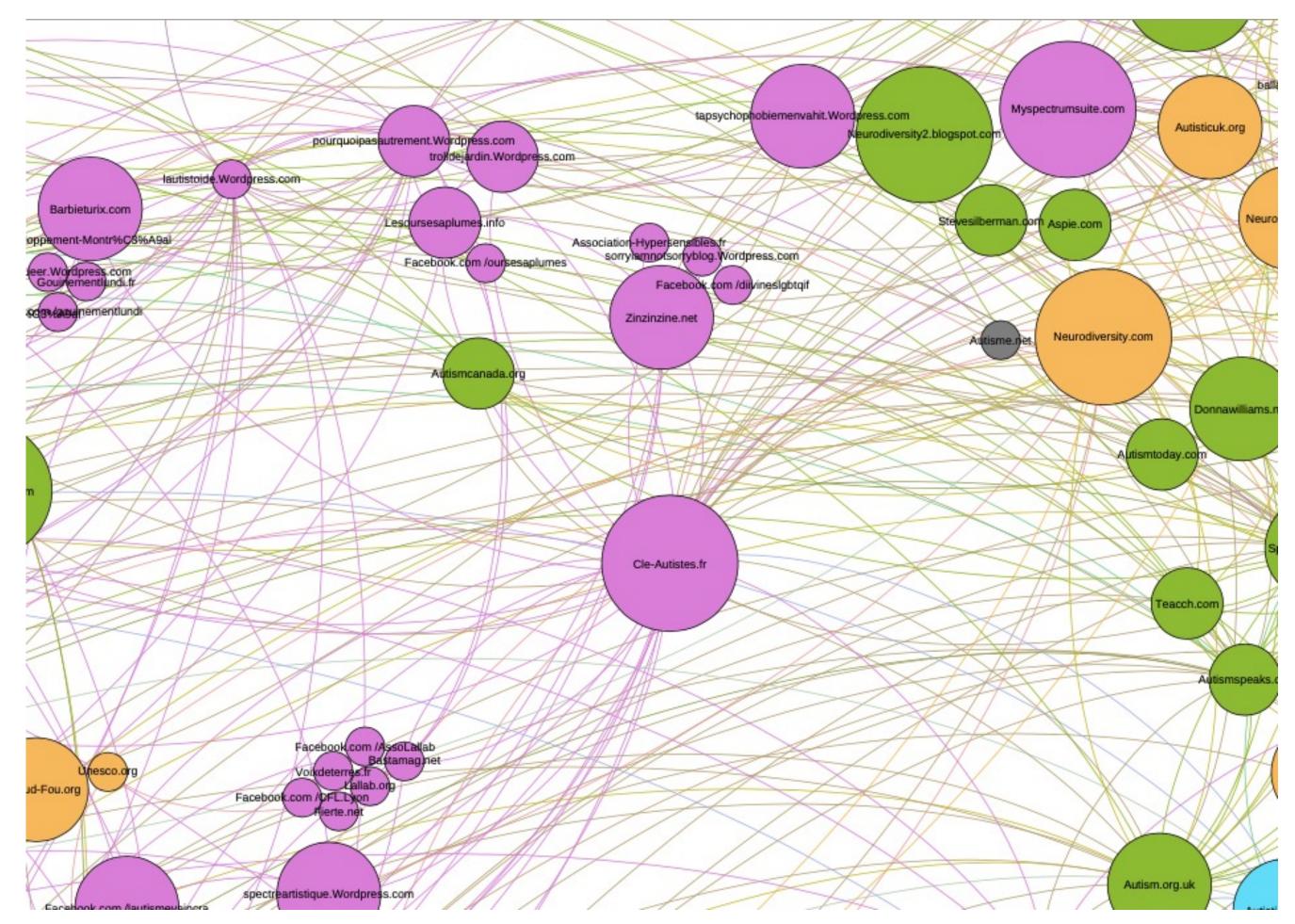
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3.3 A french activism that benefits and suffers from english-speaking activism



3.3 A french activism that benefits and suffers from english-speaking activism



4. Possible adaptations of the Web cartography for further explorations

- Leading "traces interview" : questioning their links online, observing how actors use the cartography, comparing web imagination between groups.
- Possible workshops I did not explore :
 - Asking who is not on the map and exploring politics of surveillance, moderation and anonymity
 - Asking how they have access to the map and showing hidden links of solidarity
 - Collectively imagining an ideal map



5. Possible adaptations of the Web cartography for digital activism

- Identifying possible allies for associations and public subjects to publish about
- Reactivating motivation for blogging and do "citation" politics to gain visibility
- Using the visual aspect of the map to do meditation on how the web works

Thanks for listening ③

lucasaloyse@gmail.com

Lucasaloyse.com (French website)

Fritz Lucas (2023) Cartography of the web : what are the possibilities for neurodiversity and digital activism ? Autscape, August 1st.

Hello, I am Lucas, I am glad to be amongst you all today.

Before starting, i just want to clarify the terminology: I will say "autistics" or "autistic people" according to the language used by autistics I work with in France.

-

As I described in the dedicated section in Autscape's website my presentation will be divided in 5 equal parts, each part will take 5 minutes maximum.

- first of all I will talk a bit about general aspects of what I am working on, my problematics and the directions I am looking at to answer those questions (1)

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(1)

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In France PhD thesis in social sciences lasts usually between 4 years and a half and 5 years. Being in my 3rd means I am done with observations, interviews, and presence with the actors, and I am now writing the thesis itself. As I am still processing some observations, I will not be able to talk about every aspect of my work

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So as you might know, in her book Neuroqueer heresies published in 2022 Nick Walker defines "neurodiversity" by the diversity of human brains, the « neurodiversity paradigm » by the fact that all brain are different and that there is no such thing as biologically normal brain (any norms of neurological functioning are based on cultural expectancies) the "neurodiversity movements" are the political and intellectual movements lead by people who identify as neurodivergent or neuroatypical and wants other to recognize that their neurological difference is cultural.

To organize themselves, those movements primarily use certain digital devices such as forum or social media, especially for their material characteristics of asynchronic communication, people have time to write and answer, rules of communication are clearer than face to face interaction etc

Also multiple works (Judy Singer, Blumes), testimonies (Rey Meyerding, Jim Sinclair), showed, internet was emancipatory for neurodivergent people.

This was curious because at the same time other literature (Franco Berardi, Jen Shradi, Soschana Zuboff) shows Internet as an uneven place, unwelcoming for minorities and disabled people. Social media are also responsible for the sensory and social intensity autistics might suffer from: Internet is a place of digital divide, lack of accessibility, intensification of social demands etc etc

So I was wondering what is the place of communication devices and especially digital devices in the emergence of neurodiversity movements and the recognition of the neurodivergent discourse? How autistics appropriate themselves a digital environment that was designed to a non-autistic, neuronormal user?

To answer those questions : I am using mixed methods looking both at the devices and at the people who use them.

I try to connect three levels that I will develop shortly : the level of neurodiversity as a concept, the level of the neurodiversity movements and their publics in France and the level of the body as it access to communication devices.

My first aim was to better understand the use of Internet by neurodivergent people and actor gravitating around them and to understand the dominant discourses and norms that they are exposed to online. What I did was a cartography of the web of more than 500 websites around neurodiversity and then I did an ethnographic study of certain of those web sites.

The second part of my research aim to better understand the reception and implementation of the concept of neurodiversity in an association of autistics who is in favor of neurodiversity and who has an unusual position on the cartography. I followed the association during a year, as a member of the scientific board, took part in digital activism and non-digital gatherings and demonstration.

Still with an ethnographical approach I spent a year in an institution that does not appear on the map – in France we still have institutions specialized in autism that welcome less autonomous autistics.

Spending a couple of days, a week in the institution, I paid attention to the reception of the concept of neurodiversity and its movements but also to the use of digital devices. What really matters to me was the possibility for autistic people in institution to « be part of the discussion » : how can they connect from where they are to hyperconnected self-advocated movements of autistics ?

(2)

Now that you have some elements on the three fields I am working on, it is time to focus on the one that interests us today: the cartography of the web

The web: « literally the "global (spider) web", is a public hypertext system operating on the Internet that allows users to consult pages accessible on other sites using a browser. The image of a spider's web comes from the hyperlinks that link web pages together."

It is possible to give a visual illustration of this web of hyperlinks by creating a cartography of those hyperlinks where each thread is a hyperlink and each dot a website : a web cartography.

As each hyperlink symbolizes a connection or interaction between actors it is possible to conduct ethnographic research online. You can whether look at particular interaction, look more globally on the aspect of the map or both: this is the approach I chose that is called netnography.

-You can conduct participation online seem to consist in discourse analysis but it is actually also paying attention, to the profile of users, norms of platforms and their politics : the web has publics places where people debate such as Twitter, Facebook, comment sections on digital media, it has private places where people collectively decide what to publish, where to gather and so on and so forth: every part of this web has its own accessibility, norms of moderation, etc. -You can lead what is called "trace interview", I show the cartography to actors i am interviewing and record their reaction and the way they translate what they see. It gives me information about the cognitive process through which they understand the web, the way they perceive cyberspace its danger and possibilities, and also, in details, how they use their website, the hyperlinks, and what they consider as being important or dangerous to display in public space.

Now that we have few methodological elements : how can we visualize the connections between websites ?

You can extract hyperlinks manually but it will take a huge amount of time as websites have often many many pages and it will be a nightmare to create a map out of it. So we have software to automate the process.

This tool is called Hyphe. Hyphe is a free software you can easily have access to online. You can create your own corpus that is whether private or public.

Hyphe is a web crawling software. It means that it extracts and spatializes websites (nodes) according to the links (hyperlinks) between them.

Technically it is simple to use. You give the software a couple of websites or URL that you simply paste in the box

Then the software extracts all the hyperlinks of the websites and show you all the connected websites.

You have list of discovered websites that you will then have to clean: some websites are irrelevant for your problematics or too big etc.

This operation is the trickiest because on the internet everything is probably connected to anything so you will have to choose systematically and carefully what you erase. Then you iterate and after some iteration you will have more than 90% of superfluous websites.

Finally you can visualize what you have and already conduct some analysis on that :

When you extract information from Hyphe, hyphe gives you quantitative information about the network such as "indegree" and "outdegree" from which you can already draw analysis.

Indegree conveys the number of websites from which a website is connected : a website with a high indegree is really popular amongst the network.

The outdegree conveys the number of websites to which a website direct : a website with a high outdegree is a distributor, it broadens the network. You see that before any qualitative labelling you already have important information.

Then you can extract those datas and open them in a software that is kind of similar Gephi but that enables you to categorize those websites : for example you might want to give websites led by autistics the same color, or websites that are pro-cure / against cure different colors etc etc.

It is interesting to create contrast : contrast of powers, contrast of ideology, such as the one I did with institutions around autism and neurodiversity movements

(3)

Now I'm going to show you some results cartography of the web that I did.

So what I did was I started with 100 websites dealing directly with neurodiversity and 25 institutional websites. My aim was to see if they are connections and what are those connections between institutions and pro neurodiversity websites – are they opposed as we might think ? what is the position of autistics in the map ? etc.

So I read all the websites looking for the term "neurodiversity" and classify the websites according to the frequency of mentions. Then I labelled the posture around neurodiversity : if they are in favor, against, or neutral. Then I labelled the nature of Actors : Association of Parents Association of Autistics, public dispositive, blogs, media, professionals of health, professional insertion, formation for autistics, etc..

And then the location, if it's in France, Europe outside of France, America (North America and Canada), or has multiple locations. I will show you now some of my results, but this is maybe like secondary than the method that I using and that you can use in order to build a framework for research action projects.

So I decided to share 3 results with you today

I. A very strong lobbying of associations of parents and a tiny resistance from inside the public actors.

All the pale blue dots are association of parents, you can see that they are numerous and scattered all over the map: even though we started with 75% of actors that cite neurodiversity end up with 60% association of parents which for most of them do not mention neurodiversity:

(plenty)- still have a concentration of powers around association of parents, meaning that even when talking about neurodiversiy those associations are primarly sources to understand what autism is (scattered)- representation of parents of autistic people that are more numerous but also widespread all along the networks: they especially are close to state actors such as HAS which is the equivalent of CDC in US or NICE in England, it shows the lobbying of association of parents and also the fact that online association of parents most of the time rely on the definition of biggest association to define autism and not on public actors (web is reinforcing the idea that associations are primary scientific actors around autism in France, a visitor have more chance to find those websites

- yet some public actors are in a shifty position showing different communication practices online and diverse mention of neurodiversity.

II. The concept of neurodiversity recaptured by associations of parents in an international context, as a pretext of social innovation.

even though we start with 100% French public actors we end up with 30% foreign website internationalization of question of autism, some association of parents mention neurodiversity as we can see by the size of the dots

- France is known to be late in question of autism intervention and knowledge, so since 2012 actors tries their hardest to translate neuroscientific paradigm in every layer of society : it is in this context of a rapid shift from psychoanalysis to neurosciences that neurodiversity pops up amongst associatin of parents.

- the use of neurodiversity in Canada, actors that are cited by association, of parent show that neurodiversity can be re interpreted and fit the medical model. It is the case in Canada where Laurent Mottron's work brought the concept of neurodiversity as being the talent of certain high functioning autistic people and now this paradigm is migrating toward France thought connections with association of parents and public actors. - it is a neurodiversity paradigm that is still centered on the individual brain and does not question the cultural norms of capitalist ableism: neurodiversity paradigm without movements of neurodiversity: in France as we are perceived as late in scientific innovation around autism actors tend to import scientific framework from abroad in an attempt of escape psychoanalysis.

- any attempt to bring a social perspective on autism is qualified as being destructive to "autistics communities"

III. A french digital activism that at the same time benefits and suffer from translation from English-speaking activism.

Yet actors such as CLE-Autistes tries to bring the neurodiversity paradigm in France.

But you can see a sharp devide between English speaking actors tend to cite each other's a lot and build a cluster online (media, blogs, associations) building an epistemic community and french speaking countries yet association of autistics are whether close to public actors or isolated in between islands of citations.

- actors in France tries to import concepts from the United States but as the public sphere is not familial with those concepts "stimming, masking etc" it tends to maintain them in a state of isolation (also the question of gender and queerness) also english actors do not read french

- we import the ideas but without the social structures from which those ideas emerge, which reinforce the isolation and the sensation that CLE is an outsider

(international coalition)- a continuous translation of French texts in English and a partnership could reinforce the alliances with international NGO and help them bypass the association of parents glass ceiling (local coalition)- actually CLE can mirror alliances that parents of autistics do : as they join transphobic movements, those public alliances actually offer an occasion for CLE to establish alliances with trans movements.

(4)

This was for the results on the map :

As i told you i also lead interview through this cartography : As I said I used this map to conduct observation, content analysis, identify actors and tendencies but also to lead interview from the map. Those are called "traces-interview" (Quemener 2012).

This is how I could obtained precise information on actors' opinion about neurodiversity, their feeling of isolations etc.

According to my problematics I built the interview grid in a specific way :

I was interested in how those people, especially bloggers, knew about "neurodiversity paradigm", what does it mean to them, in their personnal construct, and what are their use and representation of technological devices such as social network. I lead voice interview but also text interview throught a chat interface. I also paid attention to how the way I lead interviews build the type of profile I encountered. At some point in the interview I showed the cartography explaining how it works to the actors and ask specific questions on the relations they have with other actors based on the links I saw online and general questions on their use of the web.

Yet you can do loads of things with the cartography and actually working together on a list of questions could be super interesting : but here are the few I thought of : those are not exhaustive possibilities, only the one that I think are important to do or talk about [

- The question of web accessibility and what kind of links misses on the map : the map only represents hyperlinks and pretends that these links are the only one existing.

Depending on their knowledge of the web of their disability people might need a help to have access. So we can work on the hidden connections, the links of mutual help, solidarity between autistics and draw a parallel cartography.

For example, in my association CLE some autistics have trouble using the Discord platform for various reasons that can also cover the question of not being a digital native, so I can be useful to also understand autistics' solidarity through digital solidarity.

- The question of hidden friendships and who is missing on the map : this is a question I often asked but I felt i did not dig further enough.

Sometimes when you build a website, you miss a hyperlink or you simply forget to connect to someone, but sometimes it also expresses a will to stay anonymous or to protect someone mental health or integrity, or simply to referer to someone who does not have access to internet.

For example, you are linked to an activist but they don't appear online and it is probably because they choose not to be online for matters of ableism or else. And it could be interesting to raise the theme of digital accessibility that way.

- Instead of analyzing what is happening we can use the map to analyze what actors want to achieve in terms of alliances and friendship and we can study the political influence and agency through collective narration. So this actually overlaps with more activist perspective on how to use this cartography ...

Those are not exhaustive propositions, only things that I thought of during my work.

We can distinguish 3 levels:

- the impacts on digital strategies of associations of autistic people (1)

We can imagine collective workshops around digital utopia but I, for one, did something more unconscious and less controlled.

The first time I presented this cartography to the public it was a year and half ago and I invited the association's president to talk at an academic seminar and I showed an analysis specifically centered on the recognition of autistics' digital voices.

What happened is that it enabled CLE Autistes to identify public actors that seem to be reluctant to neurodiversity movements but that are actually in a swing state position. So they can represent them as possible allies instead of opponent.

- to help bloggers make communication choices and citation politics (2)

For example, Charlie a blogger that I met through the cartography and then I met in person in Brussels Belgium. Charlie was slowly quitting blogging because they thought it was pointless, and then I interview them and showed the connections they had with other blogs citing them or showed

the original position they have on neurodiversity overlapping psychoiversity and the orginality in their narration comparing to other blog. So it helped them identify themes they can write about and other blogs they can contact to gain visibility online.

- the third use is more an offline use to lead workshops to help other autistic peers visualize how the web works, to help them understand logics of surveillance, observation and what does it mean to be exposed online - indeed the logics of surveillance online can be a little bit abstract to grasp, and vizualizing it with a simple aesthetics of dots and threads can simplify the explanation. It can help show who cites who and who reads who, and what are the possible risks that someone runs when expressing themselves online (3)

I hope what I told you was clear enough and interesting enough to feed tour thoughts and open perspectives for the future. I am available at this address if you want to talk more about cartography and I am glad to answer the questions if you have some.

Fritz Lucas (2023) Cartography of the web : what are the possibilities for neurodiversity and digital activism ? Autscape, August 1st.