

A Future of Autism: Where are the autism communities going in society?



OR



Justin1569 at English Wikipedia / CC BY-SA
(<http://creativecommons.org/licenses/by-sa/3.0/>)

**“Urbi et Orbi” – Papal Homily
Latin for: To the City and to
the World.**

What am I calling for?

- Context
 - Autisms debates don't happen in isolation and are in fact a microcosm of wider ones in disability as well as society and vice versa.
- Astuteness
 - There needs to be a degree of preciseness and reflection on the tools that we use like Applied Behavioural Analysis and awareness raising.
 - **What are the things that people will stop at, instead of stopping at nothing?**
- Foresight
 - How do we ensure that the best solutions now won't have unintended consequences for the future?
- Mindfulness
 - When do we lead or when do we give way?

How am I calling for it?

- Explore key forces and trends affecting the autism communities and how they relate to ones in wider minority groups.
- Pose some challenges for the future for each of the different communities such as autistic people, parents and professionals
- See what are the dividing lines between communities
- Examine what common challenges the autism communities have to face
- Ask where these trends fit in to wider developments in society socially and politically
- Ask what steps can be taken both by unsuspecting victims (people new to the autism rights scene) and those who are already experienced campaigners to navigate these trends

Where am I coming from?

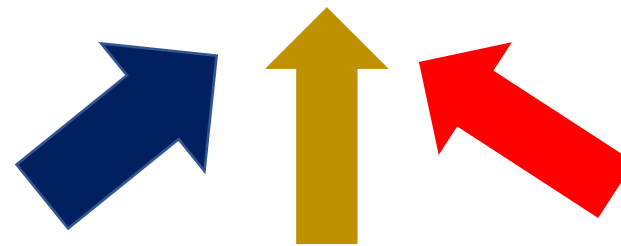
- Believer in Consociationalism- (Try to look for 90%+ instead of 50%+1 where possible)
- MA in International Security so analytical and use context.
- Remainer turned Rejoiner and Internationalist (**Member of the European Movement**) so I believe in diversity and unity through a form of accountability.
- **Descendant of victim of the Arandora Star sinking in 1940- So I hold my own side to account just as hard as I hold the other side to account. Also appreciate hidden chapters in history more because of it.**
- **Truly** started as a disability activist before doing full blown autism activism- so take a wider approach by nature.



So what are the underlying forces and factors to be aware of?

There are processes happening including...

- **Scarcity: The economy and everything that goes with it! Compounded by no deal Brexit in the UK and Coronavirus.**
- Countries beginning to confront diversity in new ways (**Black Lives Matter**).
- The world's changing and not always for the better
- **Some jobs are becoming obsolete or mutating with automation- what new ones are replacing them?**
- Generations of people on the spectrum developing their own voice and reviewing the treatments/training methods that they've been exposed to. Figuring out what's optimal.
- Rise of an autistic generation shifting from being just service users to service providers...
- Different groups of people whether scientists and self advocates moving beyond early encounters to working together...
- Power still being redistributed?



And everyone's spooked by wider historical ghosts around disability.

- **Aktion T-4: Ghost of Eugenics**

- **Sagamihara Stabbings: Mass stabbing of 19 people (including one autistic person) in a care home.**

- **Congress of Milan in 1880: Ghost of forced assimilation**

- **Little known ruling outside the Deaf Community but raises issues about who decides what's normal.**

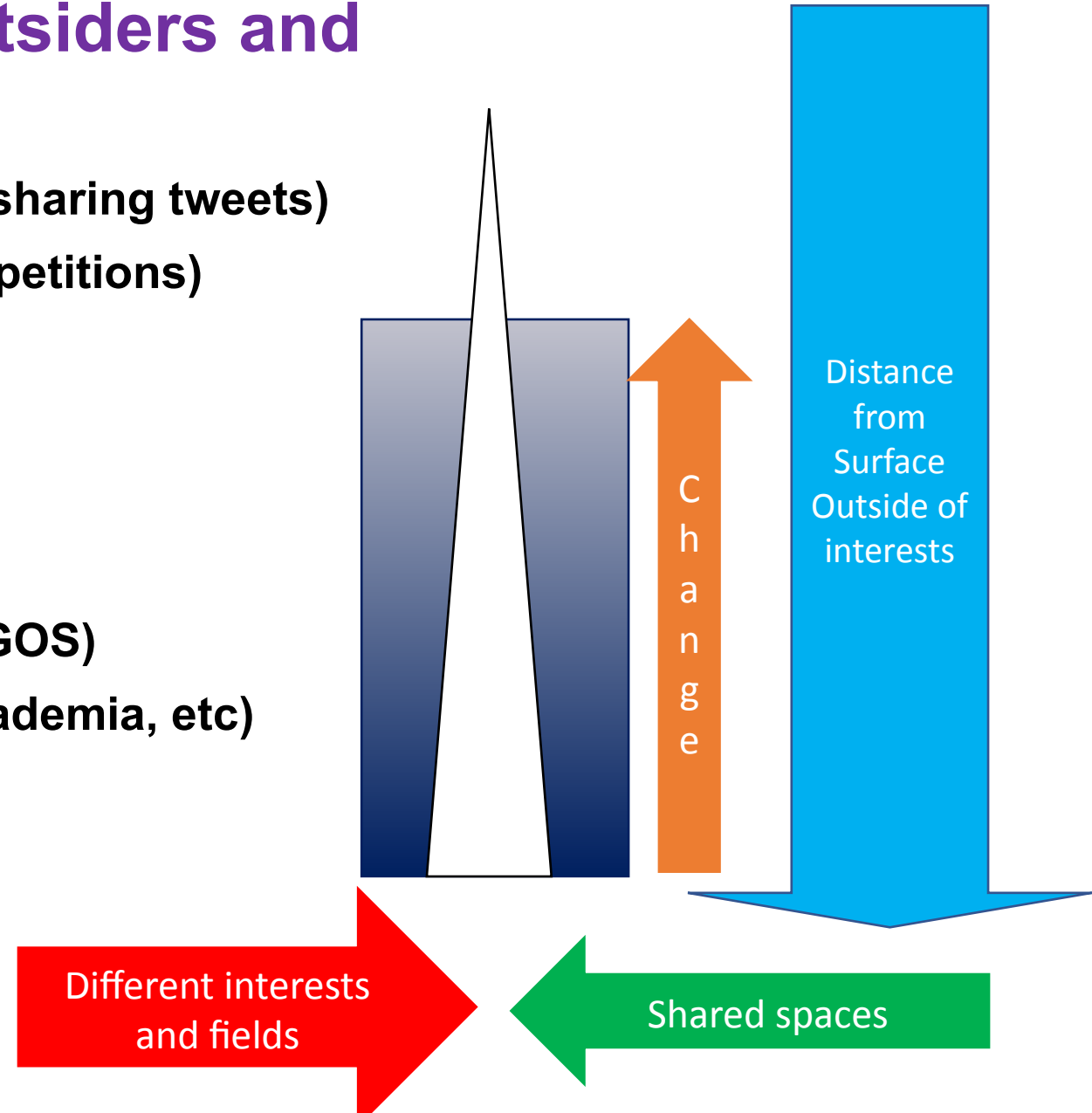
- **Parents have a ghost too: Being demonised as refrigerator mothers by Bettelheim.**

- **Everyone's afraid of being undermined by each other.**



Different forms of activism and different are affected by distance between outsiders and insiders:

- Slacktivism or outer activism (signing petitions, sharing tweets)
- The day to day (protests, social media, creating petitions)
- Front line service provision (social clubs)
- Advice (Providing information)
- Public Speaking or Ambassadorial duties
- Student/Trade Unions or Political Parties.
- The High Strategic Field (Commonwealth, UN, NGOS)
- Full time professional activism (Charity work, academia, etc)
- Elected Officials (MPs)

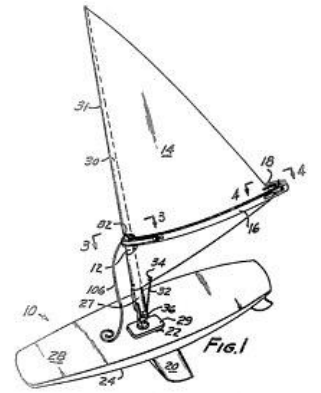


Fuelled by some other problems

- A lack of human data around autism
(My pet peeve!)
- Globalisation of domestic democratic politics.
- Although there are conflicts to be had what is being in a state of prolonged conflict doing to all of us?

So let's look at some of
the different groups...

Parents



- Took power away from professionals but are now having to share that power with autistic people themselves.
- Ghost of Bettelheim demonised as refrigerator mothers and fear further supposed demonisation by activists.- Not true but puts them in a place of being damned if I do damned if don't.
- Originally leaned to and still do lean towards more medical model although some use the social model.
- Received a rude awakening about social forces through protests and consistent challenging.
- Guilty of searching too much for the simple solution in the past and in the future.
- Can they deal with their own children taking different approaches to them?
- Can't expect advocates and professionals to back off entirely
- **Autistic people becoming parents- in fact many a story of a person on the spectrum being diagnosed because of their child. James Cusack for example.**

Autistic people themselves

- Replacing normality with something else...
- Use social model maybe an additional human rights one
- But what about those not in the know?
- Like disability community split across different fault lines and inherited wider ghosts at the same time.
- Rising grassroots and rise of a group coming through mainstream organisations at the same time.
- New wave of representation breaking through artistically.
- Can there be a better **interface** between those in the know and those who are not?
- Danger for autistic activists of following the motto “From oppression we will liberate them” not only to become the new oppressors.



By Alvesgaspar - Own work, CC BY-SA 3.0,
<https://commons.wikimedia.org/w/index.php?curid=12127693>

Charities especially the big ones

- Mixture of medical model based charities (National Council for Severe Autism) and social model ones (National Autistic Society).
- They have momentum, testbeds and resources through services.
- **Not just tokenism but no formal networks to get autistic people in the driving seat.**
- In balancing parent, non autistic professionals and autistic concerns are navigating a great passage.
- The bigger they are the less joined up they are too!
- **Facing toughest period since the credit crunch financially if not worse. So there is an opening for self advocacy organisations if they can thrive!**
- Can make people conscious of issues (World Autism Month) but can obscure ones as well as rules or conventions through what they don't mention (UN Convention of the Rights of Disabled People).
- Have their own constraints.
- **Create a wake not a wall or a big dust cloud!**
- Beginning to do more joined up thinking (Embracing Complexity)



By Norman Patrick Trickey Blake from wollongong nsw, australia - road train, CC BY 2.0, <https://commons.wikimedia.org/w/index.php?curid=26810648>

Researchers



[This Photo](#) by
Chemical Engineer is
licensed under
[CC BY-SA](#)

- Like charities failed to sufficiently confront the wider ghosts and ethical issues of their work as well as communicate them.
- **Their abyss is perpetuating an autistic version of The Congress of Milan and setting autistic rights backwards (2020 is the 140th anniversary of that conference).**
- Funding favours scientific research and is still predominantly child centric.
- **A lot of research is validation which isn't always a bad thing but...**
- **Bridgebuilding in the UK done by people including Dr Liz Pelicanoe and the Centre for Research in Autism and Education (CRAE)**
- **Consensus on priorities reached which was damaged by Autisticas participation in EU AIMS 2 research.**

So what's the common ground between the different communities or sections?

- We all have our hopes and fears...
- We're diverse and **in the same arena whether we like it or not...**
- We blur lines. Autistic people turning professional for example.
- We come from different traditions etc.
- **We're constantly bumping into new people whether they're active in the autism world or not. (Hidden Corners)**
- We're all in danger of the same or similar abysses (Security Dilemma)
- But we've all got new possibilities too including around employment and culture.

So what can unsuspecting victims do?

- **STUDY!**

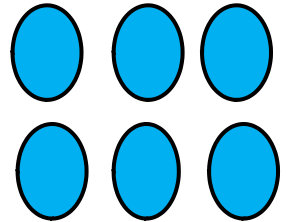
- And don't just study autism. The [Disability Archive at the University of Leeds](#) is worth a sniff
- Lots of information around, if you know where to look. Keep an eye out for and take on board different perspectives including from different groups.
- Take things at your own pace. And find your own level of involvement.
- **Look for shared spaces (even if those spaces aren't perfect).**
- Join an autism society/organisation or wider disability one
- Find a social group (or support group if you feel that way)
- Keep up to date with developments around you including in different groups
- Communicate what you're doing and how you're doing it where you can (**Especially if you're experienced**)!
- If you can come to Autscope when it returns in offline form!

And what should you avoid?

- **Believe your intentions make your actions the right ones for the situation.**
- Get obsessed by autism, particularly if you've got other interests that you're really interested in.
 - But equally...**don't ignore the call of duty either, however long it's for.**
- **Expect to get along with everyone you meet in the jungle whether they're autistic or not.**
 - **What right of way do you give though (Light it up blue/gold)?**
- Think that the ideas that you have are unique to you or tried and tested without checking them out.
- **Take any one persons view as being holy writ.** The game doesn't work that way
- **Stop at Nothing** (Know the lines you're going to cross and broadcast them).
- Lose respect for people with different viewpoints or have none to begin with- This is the key mistake that organisations like **Autism Speaks** have made.
- Apologise all the time.

For the perfectly suspecting victims among us what steps can we take towards the future?

- Communicate what we're doing and why we're doing it.
- What can we all agree **NOT** to do?
- **Create Shared Spaces (Although flawed, the Autism Show is an example)**
- **Show our consultation. (Light It Up Blue)**
- Shared ghosts (currently limited acknowledgement of T-4 by charities).
- **Talk about the interface, interface, wo-oh**
- **Be more worldly, where we can be. (Do we need an International Autistic Society?)**
- Discussion about structures as well as day to day issues (counter divorce between ideological and practical). Meaningful change and safeguards where it's not needed.
- Shared causes (Threat of de-regulation should concern all of us).
- **Comity not unity (No unified voice but a set of voices testing each other to destruction if needs be.)**
- **Maybe just maybe some kind of consensus in the distant future (along the lines of neurological dysphoria)**



Looking at things in a wider context...

- There is a real danger of a security dilemma/ double empathy trap happening in autism and beyond it over Brexit and beyond.
- How do we counter fragmentation and make sure that our democratic systems emerge from this crisis stronger and more effective than ever?
- **Path ahead is a wild treacherous coastal path with it's share of slippery parts but also some straight bits too.**
- **A global struggle and search- A clash across civilizations? I hope not...**
- **Democracy is not about “there can only be one”. It's about reconciling hopes and fears to get the best possible SET of outcomes.**
- It is also about reconciling unity and diversity through balancing degrees of autonomy and accountability.





Thanks to everyone who helped me and to all of you for hearing me out. Best of luck for the future and enjoy the rest of Autscap.