

A Guided Tour of Autism and Technology
by Barnabear, Aspie and Software Engineer
Digital Bubbles¹ – November 28th 2014

The simpler a user interface is the better.

Superhero technology has no user interface at all. I don't mean X-ray vision or anti-gravity boots. In a moment of crisis it steps out of the shadows, saves the world, then vanishes again.

This is life saving technology. Cars have Antilock Brake Systems; aircraft have Traffic Collision Avoidance System and Ground Proximity Warning System; trains have Automatic Train Protection and so forth.

Maybe you've never heard of some of these modest superheroes? That's fine, they'll save your life just the same and you won't even know.

Effective technology makes a difference. A lot may be happening in the background, but the user interface remains simple, responsive and relevant.

Keeping these in mind, I'd like to take you on an Aspie engineer's tour of technology present and perhaps to be invented.

¹ <http://digitalbubbles.org.uk/>

Technology can be a barrier, a bridge, a buffer or a filter.

Let's talk about barriers.

My mother bought a mobile phone for emergency use. She was required to make an outgoing call every 6 months or she would lose service.

Although she complied, when the hour of need arose the phone had been cut off.

The provider had changed her contract but in effect they didn't tell her.

They claim to have sent a text message about this and took her lack of reply as tacit agreement. After 3 months, they disconnected her. They then demanded a £10 reconnection fee so I went ballistic.²

To my mother a phone makes and receives voice calls and that's all she wants. She can't access text, she didn't ask for it and she doesn't want it.

This is coercing a person with inappropriate technology.

Text became a barrier to her accessing voice. One technology defeating another.

Barriers are good if they protect you or enable you to live more effectively.

I have noise cancelling headphones³. My little personal bubble of silence reduces sensory overload, giving me space to order my thoughts, reduce anxiety and become more effective.

² She didn't have to pay in the end but the provider had to sit on the naughty step for a very long time.

³ Sennheiser PXC 450

Bridges overcome barriers, and can take many forms.

The ProLoquo2Go symbol to speech app enables the non-verbal to find voice. They have control over when and what they communicate.

Automatic translators translate pretty much any language into any other language word by word. There's even a website⁴ to translate Latin into Klingon.

None can translate NeuroTypical speech, nuance and inflexion into the plain speak that Aspies and Auties long for.

How about a facial expression and body language interpreter?

Could we translate behaviour - so an Aspie can understand NeuroTypical behaviour, or vice versa?

GPS trackers provide a digital safety net for those who are liable to wander off or get lost. Some include a fall sensor. You fall over, an ambulance arrives while our techno superhero looks on from the shadows.

Even so, getting out and about can be a real problem for people on the Spectrum.

4 <https://glosbe.com/la/tlh/novem>

A couple of years ago, BBC South Today ran a series on how people's lives are affected by Autism. They report⁵ ...

A Dorset woman with autism has been told not to leave her house alone because she can't cross the road. Alex Jordan is 28 and works with computers. But traffic confuses her so much she is likely to be hit. In one year she was run over 7 times, she's broken bones and put her head through a windscreen.

Alex says "You can see them but they kind of jump about. They don't go like smooth it's all jumpy... All the exhaust fumes are different colours. The different people in them, there's so much to take in. Sometimes they don't even look like they're flowing, they look like they're jumping about and moving. Just the simple act of crossing the road is not as simple as everybody thinks."

Alex is not allowed to leave her house alone. It's one of many care rules to keep her safe.

Weekends can pass without her seeing anyone.

"It's a prison. My life is restricted by my autism... Autism sucks. Autism is just a horrible thing."

It may sound like a lonely life but that's not how Alex sees it.

"No, I don't feel lonely. I've got Facebook, who hasn't. I talk to people but some of my best friends are people I've never met."

With Google well on the way to making self driving cars a reality, it saddens me that there is not universal safe access to cross roads.

I don't know whether a guide dog might be appropriate for Alex.

What needs to be invented?

⁵ <http://www.bbc.co.uk/news/uk-england-dorset-16400901>

Unlike Alex, I can cross the road safely and I drive, but I find unstructured social interaction overwhelming. Being in a gathering with many voices speaking at the same time is an isolating experience for me.

My mobile provider sends me letters ... “Great news - you can have unlimited data, unlimited texts and unlimited calls”

Stop threatening me. Unlimited calls equals endless chatter, which is a nightmare. For me, that's an unwanted bridge.

Making a train journey involves complex planning, uncertainty and jarring sensory experiences. For some, that can be overwhelming.

What combination of technology present and future working together could equip an autistic person to achieve their travel requirements?

What needs to be invented?

Buffers provide temporal decoupling so that information doesn't have to be processed in real time.

Buffering can be a real enabler for someone on the Spectrum because it allows information to be processed at a rate that is appropriate to the user.

Email, Facebook and online fora are all buffers. These media are also a filter and a leveller because facial expression, inflexion and body language are not communicated.

An excellent example of buffering is self-paced online learning.

Whereas a classroom environment can be fraught with difficulty, an online personalized learning environment such as MOODLE⁶ is accessible on the student's own terms be it in the middle of the night in their own room or on a mobile device during the day.

I used to volunteer teaching computer engineering at an Asperger Special school and in my view, MOODLE has potential. The problem is that special schools are typically small, perhaps 60 pupils, and hence below critical mass to implement and support these infrastructures.

This is a door of opportunity that needs to be pushed.

6 Modular Object-Oriented Dynamic Learning Environment. <https://moodle.org/>

Filters

Filters allow a limited amount of communication from a larger whole, based on appropriateness. This can involve a degree of summarizing.

GPS Satellite Navigation is a filter. It takes a HUGE amount of data – road maps for the whole of Western Europe, satellite location, real time traffic – and it filters and summarizes it down to an optimal route to where I want to go.

If I take a wrong turn or the traffic changes it just recalculates. It calmly trickle feeds me just the right information in real time.

So I can delegate navigation to the device and just focus on driving safely. Ultimately, it puts me more in control.

SatNav is a huge enabler for me.

For Autistic people overloaded by the way they experience their environment, what would be an effective filter?

What needs to be invented?

Summing up

Autism isn't just a diagnosis – it's a unique way of experiencing life that creates an Autistic culture all its own. This is a good reason why many people on the Spectrum do not want a “cure” for their Autism. We want to be accepted as we are. It is not wrong to be in the minority but it can be hard.

Autscape⁷ is a residential conference organized by and for people on the Spectrum. The planning and organization takes place online.

Autism based websites provide safe islands where the Autistic community can come together in cyberspace⁸. Sometimes this leads to meet-ups “in real life”.

2 years ago I joined a web community called “Talk About Autism”⁹. UK based, this offers a safe, supportive and friendly set of moderated fora for those on the Spectrum or with an interest in Autism.

Shortly after I joined, another new member posted that she had had a very turbulent diagnostic journey resulting in a confused jumble of partial diagnoses none of which included Autistic Spectrum Conditions.

She was convinced that she had Asperger's Syndrome but having been misdiagnosed originally, she couldn't get the medical establishment to believe her. Sadly this is quite a common experience.

We started a conversation that turned into a mutually supportive friendship that has grown over the two years since. A little hand holding goes a long way.

7 <http://www.autscape.org/>

8 <http://www.aspievillage.org.uk/>

9 <http://www.talkaboutautism.org.uk/>

Our journey together has included her ...

- getting a diagnosis of Asperger's Syndrome
- founding a website¹⁰ and a Facebook group¹¹ and
- researching and campaigning for justice and better diagnostic provision for people with Autism

I am so proud of my friend and I know that she feels the same about me.

We first met in real life in January when I sold her my mother's car.

In August I drove over to her house to collect her and we travelled on together to Autscape.

We were both really nervous about meeting, but we found that our characters were exactly the same as online and we just got on really well.

We are still friends.

Each person on the Autistic Spectrum has a unique pattern of needs and strengths. The success of a technology depends on its suitability for that person and whether they are in control. It's a question of finding the right match.

Success comes in many forms, but the acid test is whether there is an improvement to that person's quality of life.

What problem would you want solved and what would you invent? These are two sides of the same coin.

10 <http://evolutian.wix.com/planetautism>

11 <https://www.facebook.com/PlanetOughtism>