

Stuart Neilson

I received a diagnosis of Asperger syndrome in 2009, at the age of 45, which was the culmination of several years of unpleasant and ineffective in- and out-patient psychiatric treatment. The diagnosis, for me, was a lightbulb moment that made sense of my feelings of anxiety in public spaces and in social settings, as well as explaining my lifelong feelings of isolation and exclusion.

Asperger syndrome is a part of the broader autistic spectrum. From my own experiences, I feel that autism maintains a strong connection with sensory experiences, at the expense of language. I can be easily distracted, or I can be intensely preoccupied by my senses. I notice changes that many people do not notice, but find it hard to cope with unexpected change. Busy places with lots of lights and noise can be very hard, and make communication very hard work. These pictures try to capture my sense of place and movement.

The word pictures use articles about autism from the Irish Examiner, Irish Times and Irish Independent over the past fifteen years and text from medical textbooks to examine how people talk about autism. Written portrayals not only describe autism, but also shape how autistic people are perceived and treated. Careful use of language helps to shape a more inclusive, respectful and tolerant attitude to difference.

I lecture and write about the autism spectrum, both as a health statistician and from my personal perspective. I was a founder member of the team that developed the innovative Diploma in Autism Studies at University College Cork, Ireland. I have a degree in computer science and a doctorate in mathematical modelling of inherent susceptibility to fatal disease.

My most recent publications include `Living with Asperger syndrome and Autism in Ireland', `Painted Lorries of Pakistan' and a chapter on sensory issues and social inclusion in the anthology `Knowing Why: Adult-Diagnosed Autistic People on Life and Autism'.

You can read more about some of the ideas displayed here at my website, wordpress.stuartneilson.com and about the exhibits at stuartneilson.com/creatingautism/.

* Cover image: **Grand Parade to Patrick Street**: Using a moving vehicle as a scanner, this image captures the entire street façade of Grand Parade and Patrick Street. The image is a travelling video slit-scan combining pixels from video frame selected according to 'visual change', i.e. discarding all frames when stationary, some frames when moving slowly and none when moving fast - or when the image is more complex or visually interesting. Map data © OpenStreetMap contributors

Autism: Nature, Perception, Word

Autism is a collection of natural phenomena, a syndrome of traits and behaviours that arise from neurological variations in early development. A combination of sufficiently clear autistic signs, in a particular set of combination, will be perceived by a trained observer as 'autism' and then assigned a particular diagnostic label for future intervention.

Autism is a set of perceptions and portrayals of autism, as specific characters in fiction, as stereotypes of what autistic people are like, and as psychiatric and educational expectations of how this diagnosis is managed.

Autism is a word, a symbolic shorthand used to simplify communication about a complex world of perceptions and phenomena into clear and concise language. 'Autism' is a special educational need and a residential care plan.

Autism exists simultaneously in multiple, overlapping plains - natural phenomena, perceptions, and words - that serve to both highlight and to obscure the people who inhabit the label. Being autistic means having some elements of the diagnostic criteria that make up autism, but in a unique and individual combination. Being labelled 'autistic' is a key to intervention and understanding, but the label also obscures the human complexity of the person who has been labelled. No two autistic people are alike.

Autism has changed dramatically since it was first used in its modern sense, and the label continues to evolve with scientific enquiry and professional experience. As a result, when two different people say 'autism' they are probably saying two different things. The autism of 2019 is not the same set of phenomena or perceptions as the autism of 1952. The autism portrayed by the character Raymond Babbitt (Dustin Hoffman) in 'Rain Man' in 1988 is not the same as the autism portrayed by Billy Cranston (RJ Cyler) in 'Power Rangers' in 2017.

Autism, being bound to perceptions, portrayals, individuals and events, means different things in different places. The presence of genetic research, community support, special educational resources, personal tragedy or charismatic autistic speakers all colour the reporting and representation of autism at specific times and in specific places. Self-image and self-worth are also coloured by public representations of others who share the same label. The attitudes toward people labelled with autism are shaped by public representation.

Choosing how to talk about autistic people – and the words are most definitely a choice – has a profound impact on how interventions for autism operate and how autistic are perceived and integrated within society.

History: The Changing Definition of Autism

The definition of autism is exemplified by the diagnostic criteria and descriptions within the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association in seven editions from 1952 to the present. The DSM is one of the main guides to what 'autism' means, at the present time, in a medical setting.

The 'autism' we know right now is not the same as the condition outlined through case histories by Hans Asperger in 1938, or by Leo Kanner in 1943. It is not the autism of DSM-I in 1952.

Medical criteria have been supplemented by film depictions since 1963, by fictional books, by television and (most recently) by autistic people in autobiographical works.

Those changing definitions and descriptions of autism both reflect and shape the way we identify and perceive autistic people.



Alluvial Plot of Autism Terminology

The top 60 words in all seven editions of the DSM, from DSM-I in 1952 to DSM-5 in 2013. The most frequent word in each edition is at the top, showing how word-frequency flows, river-like, over time and between editions. The word 'spectrum' was introduced for the first time in 2013, 'Asperger' in 1994, and the use of 'schizophrenic', 'reactions' and 'disturbance' have declined or ceased.

Like the Ship of Theseus, little remains of the original definition. "I believe that the autism narrative genre is helping to bring into being an entire mode of discourse, cementing ways in which we have recently begun to talk, and will talk, about autism. It is developing a language, or, if you will, a new language game, one that is being created before our eyes and ears. This speech is, in turn, creating or extending a way for very unusual people - namely autistic ones - to be, to exist, to live."

— **Ian Hacking (2009)** "How we have been learning to talk about autism: A role for stories". Metaphilosophy, 40(3-4):499-516.



Starting Line

A rower prepares to compete in the Head of River, turning to look (back) to the finish line, as multiple competitors speed downstream in the distance. Sea birds move at a different pace in the misty drizzle overhead, while off-duty sea fishing vessels rest at the quays.

The video composite combines equally spaced elements of change in the scene.



Bus on Parliament Bridge

The sinuous path of a bus rising over Parliament Bridge before turning onto South Mall.

A video slit-camera scan captures the very bus-y-ness of the vehicle's route as its path curves over the bridge and around to the junction.



Head of the River

A sequence of overlaid images convey the sensory experience at the Head of the River, near Kent Station. The light fog, the smell of sea weed and diesel at the docks, the shouts of encouragement and the call of gulls, the fluorescent yellow paint and rust on the bollards, and the historical buildings high on the opposite bank all contribute to a sensory memory of an extended moment in time.

Geography: Autism, Emotion and Local Events

Autism means different things in different places. Even within the island of Ireland, the words used around autism vary tremendously. Local events such as medical research, court cases, fund-raising, community services and the achievements of individual autistic people all feed into a local impression of what autism means, now and here. Growing up autistic in Munster, surrounded by the news about autism in Munster, is likely to be a different experience than growing up autistic elsewhere in Ireland.

Words also carry emotional associations, or baggage, from their common usage. These generate an emotional tone or sentiment toward autism that varies between places.

Individual autistic identities and self-worth are affected by the words and emotions other people use to describe, identify and respond to both autistic individuals and autism in general in their locality.



Autistic Ireland

The predominant words in newspaper articles over the past 15 years are each placed into the province in which they are most frequent, at a size representing the word frequency. The emotional tone of the words used in news - trust in experts, anger over resourcing, fear of disease or joy in community - are as real and potent as reported events, such as the Autism Brain Bank, funding cuts, Jamie Sinnott's court case or the Cork Association for Autism annual fundraiser.

"And then came the grandest idea of all! We actually made a map of the country, on the scale of a mile to the mile!"

"Have you used it much?" I enquired.

"It has never been spread out, yet," said Mein Herr, "the farmers objected: they said it would cover the whole country, and shut out the sunlight! So we now use the country itself, as its own map, and I assure you it does nearly as well."

— Lewis Carroll in 'Sylvie and Bruno Concluded'



Grand Parade

Bus Eireann public transport and a Calor gas truck passing the monochrome granite blocks of a pedestrian crossing. Streams of traffic alterante with streams of pedestrians. A polar spiral, $i=cos(\sqrt{x})(\sqrt{x}/K+y), j=sin(\sqrt{x})(\sqrt{x}/K+y)$, elegantly fits the image into a square frame.



Singer's Corner

Many pedestrians do not use the planner's preconceived boundaries at Singer's Corner, Grand Parade. People's Desire Lines run outside the box. The video composite is colourised with motion heat-map of the scene.



"This is Me" (Cork LGBT+ Pride Parade 2018)

From the opening Garda escort motorcycle and "This is Me" balloons, 1.6km of parade passes a slit-scan camera on Patrick Street, spiralling in to the closing Garda escort car. The image is created from just over 16 minutes of video, creating a 32 megapixel image 29,700 pixels wide.



Cork Airport Sculpture

A bus journey to Cork Airport, passing five brightly coloured sculptures representing stages in the construction of a paper aeroplane. Multiple overlaid images capture the sense of the journey, dominated by visible features, trees, the weather, road signage and colour.

Perspective: Writing about Autism

Words exist in a complex network of language, guiding and directing sentences into familiar patterns of usage. There is no 'correct' way to talk about autism, because language serves conflicting purposes depending on the context and the speaker. Clear, concise and effective communication will always demand different language in different settings.

'Common use' is like a groove, and following the groove is the easy path, reinforcing both common understanding and common misconceptions. Even choosing one preferred term - 'autistic' over 'autism' - can have a profound impact on the way the surrounding words form themselves. It is hard to say "managing autism in the classroom" if the word 'autistic' is preferred.

Consciously switching to another linguistic groove has a dramatic impact on language, dropping one set of perceptions and mis-conceptions in favour of another. "Reclaiming the metaphor", by using existing familiar language in new ways, may be easier than creating unfamiliar new terms. Choosing respectful, empowering images that accurately reflect autistic people may ultimately liberate us from the 'euphemism treadmill'.



Autism (noun) or autistic (adjective)?

How newspaper journalists write, and how the structure of language guides the words.

'Autism' (a noun) can stand alone, usually following a preposition or conjunction (and autism, in, of or with autism), while 'autistic' (an adjective) demands a (usually human) subject must follow.

This network graph is composed from word-pairings in 2.3 million words from all the autism articles in the Irish Examiner, Irish Independent and Irish Times over fifteen years.

"The euphemism treadmill shows that concepts, not words, are primary in people's minds. Give a concept a new name, and the name becomes colored by the concept; the concept does not become freshened by the name, at least not for long. Names for minorities will continue to change as long as people have negative attitudes toward them. We will know that we have achieved mutual respect when the names stay put."

- Steven Pinker (2009) in 'The Blank Slate: The Modern Denial of Human Nature'.



Creating Autism

The title "Creating Autism" emerges from a collage of text torn from pages defining autism in the Diagnostic and Statical Manual of Mental Disorders, overlaid with autobiographical text written by autistic people.

Language is plastic, continuously adapting and changing to suit new uses, sometimes rising towards a joint linguistic enterprise, like the Tower of Babel, before collapsing again to create fresh raw material for others to shape.



St Gobnait's Well, Ballyvourney

St Gobnait's grave is marked by the sign of the cross, traced by pilgrims three times over each of three crosses. The markings represent a current consensus of where the crosses lie. Nobody can know where the first pilgrim made the first cross, or how the first three crosses were arranged. The current paths, deeply grooved, guide the hands of current pilgrims into repeating the consensus, much as a vinyl record guides a needle to repeat the song.



Memory

Lichen grows outward in rings at 1.2 mm per year, gradually brightening the inscription on a headstone in St Michael's graveyard, Blackrock.

This lichen ring represents decades of elapsed memory, and across the graveyard there are layers of lichen and moss enriching layers of inscribed memory.

(Re)Creating Autism: Autism Narrative

The number of books published 'about autism' or including more-or-less 'autistic' characters has risen from 1 or 2 titles per century to tens or even hundreds of titles per year now. Twenty or more mainstream films with an autism theme are released every year. Autism **fiction** has surpassed text-books and **non-fiction** as the overwhelming source shaping autistic identity.

The vast majority of 'autism' in fiction is written by, and intended to entertain, a mainstream majority of non-autistic viewers and readers. Autism and autistic characters in fiction are most often metaphors of hardship, social exclusion, global change and other mainstream themes. Fiction rarely depicts the experience of real autistic lives.

Fiction succeeds or fails on the degree to which we, the audience, affirm or reject themes and depictions. Fiction is also a product of imagination and experience — in this case, experience with real autistic lives. Autistic writers, actors and documentarians are gradually being recognized, bringing their own perceptions and priorities with them.

We can reclaim the metaphors, affirm and reject depiction, and offer up our own experiences for imaginitive writing that creates a better autistic future.



Growth

The number of books featuring 'autistic' characters has grown from 1 or 2 per century to many tens of titles per year. From early 20th Century psychiatry to 21st Century feature films, the portrayal of 'autism' is growing explosively, and the image of 'autism' is transforming radically. Autistic titles (written by, starring, or directed by autistic people) are a small, but growing, fraction.

(1726) • Gulliver's Travels by Jonathan Swift • (1802) • Victor, the Wild Boy of Aveyron by Jean Marc Gaspard Itard • (1853) • Bartleby, the Scrivener by Herman Melville • (1897) • Captains Courageous by Rudyard Kipling • (1924) • The Outsider by H.P. Lovecraft • The Sound and the Fury by William Faulkner • (1929) • Passing by Nella Larsen • (1937) • Of Mice and Men by John Steinbeck • (1938) • Rebecca by Daphne du Maurier • (1945) • Pippi Longstocking by Astrid Lindgren • (1950) • I, Robot by Isaac Asimov • (1955) • The Story of Sandy by Susan Stanhope Wexler • The Birds by Tarjei Vesaas • (1957) • Verbal Behavior by B.F. Skinner • (1959) • Flowers for Algernon by Daniel Keyes • (1960) • To Kill a Mockingbird by Harper Lee • Dibs in Search of Self by Virginia Mae Axline • Martian Time-Slip by Philip K. Dick • (1964) • Sanity, Madness and the Family: Families of Schizophrenics by R.D. Laing • (1965) • Empty Fortress by Bruno Bettelheim • (1966) • Why Johnny Can't Read-And What You Can Do About It by Rudolf Flesch • (1967) • The Siege: A Family's Journey Into the World of an Adulstic Child by Clara Claiborne Park • (1969) • On Death and Dying by Elisabeth Kübler-Ross • (1970) • The Bruno Bettelheim • (1966) • Why Johnny Can't Read-And What You Can Do About It by Rudolf Flesch • (1967) • The Siege: A Family's Journey Into the World of an Autistic Child by Clara Claiborne Park • (1969) • On Death and Dying by Elisabeth Kübler-Ross • (1970) • The Summer of the Swans by Betsy Bysrs • (1973) • The Climate Stranger The Autistic Child by Carl H. Delacated. What to Do about Your Brain-Injured Child Clare Delaced on the Commerce of the Swans by Betsy Bysrs • (1973) • The Ultimate Stranger The Autistic Child by Carl H. Delacated • The Rat A Study in Behavior by S.A. Barnett • (1975) • Howie Helps Himself by Joan Fassler • (1976) • Son Rise: The Miracle Continues by Barny Neil Kaufman • Steps to Independence: Teaching Everyday Skills to Children with Special Needs, Fourth Edition by Bruce L. Baker • (1977) • Magical Child by Joseph Children Pearce • Along Came Spider by James Preliefer • The Basketball Diaries by Jim Carroll • A Swiftly Tilling Planet by Madeleine L'Engle • (1978) • Music Therapy for the Autistic Child by Joliette Avin • Sensory Integration and the Child: 25th Anniversary Edition by A. James Freiene • The Basket • (1978) • May Schole Children Pearce • Along Schole Children Pearce • Along Schole Schole Children P

Techniques and software

I am a statistician, mathematician and computer programmer, so I have used the tools I know to make the images I want to share. All the techniques I have used are published methods and all the software is Free and Open Source Software (meaning you can download and run the same code, with a little technical expertise).

In particular, I have used the following packages:

- **Graphviz** to assemble word bigrams into networks representing frequent word usage
- Perl to massage large volumes of text the Irish newspaper stories about autism used in the images here amount to 30 MB of text, containing 2.3 million words about autism published over the past fifteen years
- The statistical language R to analyse word frequencies and generate images, such as the alluvial and map plot
- Bigram and Ngram analysis to generate word usage patterns these
 widely used statistical techniques are fundamental to many modern
 internet processes using natural language as input, including internet
 (e.g. Google) search engines and automatic language translation
- Sentiment analysis to estimate the emotional content of a news stories about autism, using Saif Mohammed's NRC Word-Emotion Lexicon
- **OpenCV** (the Open Source Computer Vision Library) and **Python** to analyse moving video and generate simulated slit-camera and motion-mapping imagery
- ImageMagick to process and combine images into their final form

These tools give me a sense of objectivity, because I feel that I am using a machine that repeatably generates the same output over and over, whoever was operating it. I am aware that my sense of objectivity is false, and these images are subjective and personal — just as the word 'autism' conveys a sense of scientific objectivity, disguising the equally subjective, diverse reality of autistic experience.

Slit-scan images

The slit-scan camera, in its original form, moved a strip of film beneath a narrow vertical slit on which a moving image was focused. Anything

moving past the camera leaves a trace, for instance verifying the athlete first to cross the finishing line or the intertwining of two dancers.

The scans here use video (taken with a DSLR and a mobile phone), extracting the central vertical 1-picxel-wide column through the centre of each frame - imagine using a computer scanner outdoors as a camera. In a uniform image (e.g. "This is Me"), each pixel is the centre of each successive frame of the parade passing my camera mounted at a fixed point on Patrick Street.

Some images play with 'change' or 'stimulus', instead of uniform time. A frame only contributes to the output scan if there is sufficient change between successive frames, or since the last frame that was selected. Passing a street facade in a moving vehicle, the shops only contribute to the image only when when at least (say) 20% of pixels have changed. Sitting at the traffic lights does not contribute to the output, and driving slowly contributes less than driving fast. More playfully, 'interesting' features, frames with large visual stimulus, contribute more. An object is wider if it is visually stimulating and narrower if it is featureless.

Video montage

Video montages are made from a small number of selected frames within a video, either simply widely spaced or chosen because they are very different from one another. I combined frames by calculating first the darkest elements (the minimum of the selected frames) and the lightest elements (the maximum), and overlaying these extremes with a soft light mode.

The effect, to me, is like a visual tone poem of the place, or even the event or journey recorded in the video. It amazes how much of the place, time and activity are recognizeable and how unlike the montage is to a more typical photographic record of a moment in time.

Strobe effect and heat-mapping

I am fascinated by Desire Lines and the paths that people occupy in shared space, often far outside the architectural and functional lines that planners intended to bound activity. Who crosses within the lines of a crossing, or walks parallel to the edges of the paving? Desire Lines appear in grass, on Google Earth, in the snow and wear patterns in carpets or stone.

Using video from a stationary camera, I calculate the areas of change between frames (or between individual frames and the background), to extract the pixels of objects in motion. There are some amazing operations you can perform on change pixels. Extracting the change pixels of equally spaced video frames and overlaying them (as above, the soft light overlay of the frame minimum and maximum) gives an effect like a strobe - in any lighting.

Counting change per pixel, i.e. the number of times a pixel differs between

frames, measures the visual stimulus of a scene. The change count can be colourised, to give a false-colour heat map of a place – a classroom, workplace or shop – to show how people and crowds occupy space.

Outlining change pixels (i.e. selecting the pixels that change between frames and drawing an outline of the shape) shows whether objects overlap. These might be two students sharing contested desk space, or pedestrians on intersecting Desire Lines, or wild animals at scarce water. The coloured-in outlines of changes look surprisingly like ancient cave paintings.

Word map

The word map is made from the most frequent words in news reports about autism or Asperger syndrome in Irish newspapers over the past fifteen years. The words are sized in proportion to the word frequency, and placed in the province with which they most frequently co-occur. The position within the province is random, starting from the most frequent word and continuing until the province area is filled and no further words fit.

Alluvial (river) plot

The alluvial plot is a modified form of the alluvial time-series plot in R, generated from the frequency of the most common words in the full text of each edition of the DSM. The text includes the overview, diagnostic criteria and full description of autism, Asperger syndrome and autism spectrum disorder (or equivalent) in each edition.

Autism word network

The words (nodes) are sized in proportion to word frequency, selecting the most frequent words used in newspaper articles that include 'autism' and newspaper articles that include 'autistic'. The words are connected by a line (directed edge) with a width proportional to the co-occurrence of the pair of words (in the direction of the arrow). The words and lines are coloured according to whether they occur more often with 'autism' or with 'autistic'.

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