

# Creating social space for autism

# Am I autistic?

- I was a rather monotropic (attention tunnelled) child, language especially writing being my (socially approved) passion
- For your amusement,
  - Here are my fingers: index finger noticeably shorter than ring finger
  - I score in the highest “normal male” range in the AQ test; 0 in the male/female tests (I’m a mother of three) [... parlour games]

I am going to presume to say “we” and mean autistic people - though I have also written and spoken from “the other side”.

If what I say seems wrong, please tell me:

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Your comments are welcomed and may - with acknowledgement - modify this presentation

Why do we need to make  
social space for autistic  
people?

Because people at present  
believe that autism is “a  
terrible disease” - or at best a  
disabling dysfunction that  
needs fixing↑

David Vardy (a parent) - claiming to speak on behalf of autistic people in Canada

"Autism is worse than cancer in many ways, because the person with autism has a normal lifespan. The problem is with you for a lifetime."

quoted by jypsy see below for link

# Autism is a disease?

## **No!**

Probably everybody here knows that autism confers many strengths.

How could such a condition be disease?

# Defined by dysfunction?

- Diagnostic criteria are all about “deviation from a norm” which is regarded as desirable
- “The desirable norm” is a harmful idea which discredits the abnormal/atypical
- There is no reason to think that the more normal - the nearer the middle of a statistical distribution - someone is the better they will be (or the worse)
- There are strong reasons for thinking our species benefits from variety (all species do)

# Defined by difference

- Different performance on a variety of tasks
- Persistent negative interpretation of results
- Odd world in which children not lying is seen as bad news!



# Two-way improved understanding is needed

- Mutual understanding
  - people typically do not understand each other well
- Personal understanding
  - Typical people AND atypical people do not typically understand EITHER typical people OR atypical people well.
  - Typical AND atypical people do not understand themselves well
- Both misunderstanding and non-understanding are rife
- People of all sorts do sometimes understand each other beautifully

- We - by which I mean primarily Mike Lesser and myself, and more recently Wendy Lawson and Sebastian Dern have personally found that an interest theory of mind has been repeatedly useful in making sense both of other people and of ourselves.

# Conceptual model

- There is a more strictly defined mathematical model of mind as a dynamical system available at [www.autismandcomputing.org.uk](http://www.autismandcomputing.org.uk)
- That model requires much development [**any programmers/mathematicians out there want to help?**]
- The model referred to in the current presentation is the conceptual version of an interest system as we imagine it: it conforms to and we anticipate can be reproduced within the mathematical version

# People

- $\top$  Forget the black boxes and simple one-way arrows of cause and effect, it just isn't like that
- Think of other people as collections of often co-active interests with energetic flows travelling in a variety of directions and the whole picture becomes messier but more like the real thing

Ours is not a model of autism it is a theory about human beings in which autism has a natural role as contributing to essential diversity. The interest model of mind is a new way (graphic, mathematical) of conceiving of people as **transient collections of desires/directed energies affecting and being affected by perception, imagination, cognition and action.** We think it makes psychological data (people) easier to analyse.

# ... different model

- No claim that all meaning is necessarily social  
- rather meaning derives always from interest
- No definite boundary between conscious and unconscious - the boundary at any time depends on current distribution of attention
- Ego is not central but merely one of many other interests

# Autism challenge

- The model has informed our view of autism:
- Trying to understand autism has been a great challenge starting with the initial thought that maybe instead of tending to have a lot of interests coactive, autistic people may be 'attention tunnelled'
- Back in 1991 we started looking at autism by focussing on the negative because it gets all the attention in 'the literature' (as in life) - but many positives for monotropic dispositions are implied in the model

# Implications for autism

- Everything is possible - anyone can eventually learn anything.
  - “Empathy and the engineer”
- Interest systems evolve over time
  - More and more connections are made, people tend to move away from the deepest monotropism, simultaneously acquiring more widely useful knowledge and tending to lose their ‘edge’, learning to adjust their mind set and thus their behaviour so it has a better fit with society



# ... different model

- No fixed timetable of development - rather we observe wide variations in speed of development
- BUT while steep interests may yield great results, they may also channel energy away from activating key skills during their optimum learning period, resulting in non-automatic strategies which are functional but impose a high system demand.

# Extra system demand

Autistic people:

- A] can and often do learn later on than most people abilities such as language use (including the reading of and presentation of body language) self-monitoring, and monitoring who is interested in what;
- B] tend to find that deploying those abilities is at a high cost because doing so requires constant awareness.

- A monotropic disposition tends towards concentrated energy, energy travelling in one direction - eg towards task completion,
- as opposed to spread, multi-tasking distribution
- Makes things happen
- Requires internal consistency/coherence
- Can also choke up, or become overloaded
- Will not be swiftly turned off
- Can be experienced as “minding too much” or “becoming over excited” (too much for me or too much for other people? - often both see below)

# Overload

- Overload can be through any channel
- Excess demand may be in sensory, social, motor or other channels, or any combination thereof
- Demand may be for both processing and performance: the same resources fuel cognition, emotion, imagination and action (including speech)

# Monotropic flow

- Does not mean narrow scope, but intense concentration
- The interest which generates this flow may just be the desire to know What's Going On?
- Or it could be the desire to know What is The Meaning of Life The Universe and Everything?
- Or it could be the pleasure of contemplating, say, this bit of carpet...

# Monotropic flow

- does NOT equal a lack of drive for ‘central coherence’
  - this is not a coherent idea: there is no “central”
  - logical incoherence or inconsistency are more strongly felt by autistic people
- Its process may generate vast tracts of new structure, new foundation for the next thoughts
- It may “beat new paths”

*Aut viam inveniam Aut faciam* Latin for "I'll either find a way or make one" from Hannibal in the second century BC (*Autistic Underground badge, available with others from <http://www.cafepress.com/oddizmautistry>*)

# Prediction

- Everyone will tend to be faster on unitary tasks than they are on multiple tasks
- This is certainly true for monotropic states
- The gap between unitary and multiple tasks will be significantly wider in people with an autism diagnosis

# Prediction

- Autistic people will tend to be faster and more accurate than controls on the unitary tasks

and/or

- Autistic people will tend to be slower in switching tasks but will tend to retain greater accuracy



⊥ Superior autistic performance  
- NB nobody should need to perform well in order to have their basic human rights recognised

List below as well as above point thanks to Michelle Dawson, see <http://www.parl.gc.ca/38/1/parlbus/commbu> for the context

- **superior performance in detecting and responding to visual social and non-social cues**
- **faster sentence comprehension**
- **superior performance in detecting changes in pitch**
- **enhanced memory of semantic and visual stimuli with less susceptibility to false memories**
- **↑**

- **enhanced visual search abilities**
- **enhanced visual discrimination**
- **superior ability in disembedding figures**
- **enhanced auditory pitch memory, pitch labeling and pitch disembedding**

- **superior speed of processing**
- **superior pitch discrimination and categorization**
- **superior accuracy in graphic cued recall**
- **superior phonological processing**
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# Why improved accuracy?

- No pressure from having a lot of different pre-informed concerns creating expectations - ergo unprejudiced observation
- Typical people are prejudiced observers (there is a huge literature on this) they share a myriad of assumptions and import these along with their hopes and fears into both their perceptions and their discourse

Evidently autistic people are no more dysfunctional than anyone else - it's just a different pattern

–Why with all this potential do things so often go wrong?

# Why don't autistic people flourish in our society?

-Would eg good eye contact or knowing how to flirt improve respect and inclusion?

[possibly, with a lot of luck...]

- More useful would be learning how to avoid being discombobulated



To be discombobulated = to  
be temporarily totally robbed  
of the capacity to think or act  
effectively

# prediction

- Discombobulation will occur more frequently in people with monotropic dispositions
- May be felt especially intensely by people with monotropic dispositions
- Periods of discombobulation are likely to precipitate diagnosis

# Why does discombobulation happen more often in autism?

- ⊥ Because we live in a crazy world
- Because monotropic interest systems are disposed to overloads and bottlenecks
- Because monotropic interest systems dispose to extremes
- Because when you are entirely concentrated on X you do not anticipate R, A or O (etc)
- Because we mind \*so much\* when things don't go right

- Because multiple alternative interests and their energy and stored information are less likely to be available to monotropic individuals, no alternative viewpoint is readily available: so **recovery time is longer**

## In our model

Each such event will also have the effect of “weeding out” the weaker interests and building up the stronger ones because the mess after meltdown will tend to recover/ self-sort towards the strongest attractors, tending to leave the weaker ones unactivated and liable to extinction

- “Fragmented world” - everyone has bits missing, but this may not affect the overall picture until the missing bits affect one’s perception/understanding in a way which causes trouble - ie **there is no fragmented awareness except in catastrophic situations**

∇ ⇒ Relatively frequent discombobulation

- Most people (NTs) have their areas of well-founded certainty woven ‘elastically’ together with soft wobbly beliefs, many based on hearsay, ie although their awareness is incomplete it rarely seems so to them

∇ ⇒ Relatively rare discombobulation

# Focussing on the negative - the moments when things go wrong

- Negative events draw attention to themselves - universal truth
- When things go wrong we tend to notice; when things go right we don't have to think about them so we don't have to notice them - there is a dramatic difference in the amount of attention called for - although with a proper happiness seeking attitude **we will also rejoice and feel awe at the wonder of creation**

# When things go wrong...

- Minding **too much**
- Getting **too upset**



# From one's own viewpoint

- Discombobulation - inability to speak or react effectively or feel anything but helplessly BAD BAD BAD
- Feeling bad or being bad?

# From 'Society's' viewpoint

- Challenging behaviours
- Autistic behaviours
- Behaviours we [Society] abhor!

# Parental worries

- Normal developmental timetable
- - recent invention: considerable variety used to be accepted, eg there were known to be late talkers and early talkers.
- New awareness--> new worries:

# Self-fulfilling expectations

- Always expecting the worst = creates negative outcomes [cf performing rats - same rats, 2 groups - one research group told they'd been bred to be clever, the other the opposite. The rats conformed to the expectations ]

# Parental worries

- Basic worries hyped up
- How much “support” will my child need?
- Will they have friends?
- Will they have a partner?
- Will they have a job?
- Where will the support come from?
- How good will it be?
- How long will it last?
  
- Will my child be One of Those Monsters?

# images

- The missing piece
- The distressed child
- The 'challenging behaviours'
- The 'aggression'

# Statement by Jordan & Jones re Make Me Normal

- “Imagine a programme called 'make me white' and a school that taught black children that they had no control over their behaviour because of their blackness and this would be something that would both blight their lives and make sure nothing good happened to them. The outcry would rightly be enormous and in fact there is no way such a programme would be made”

# “Why did you always run away?”

- “Because you hated us...”
- Kid at party... (empathy/telepathy/motivation story)
- missing the context but potentially very affected indeed by feelings



# The Story of Alex Bain and...

(I talked around this, especially re jypsy's activism vis-à-vis school)

## New possibilities Alex's story



ALEX BAIN TYPES HIS CLASSMATES' NAMES ON CANNON COMMUNICATOR

- At 4 years old Alex didn't talk. Assessments around that time report little to no eye contact, frequent significant temper tantrums, no expressive speech, language, communicative intent or "appropriate social interaction". When Alex was diagnosed we did not view him as a collection of deficits. We accepted that we had a very different child with a very different road ahead than that of his siblings and peers. We assumed competence. We recognized and worked with his strengths.

He started talking when he was 6,  
mid-way through grade 1. A  
classmate taught him to talk. But  
just before he turned 4, using  
Augmentative Communication,  
Alex began to type...

see

<http://www.isn.net/~jypsy/AuSpin/senate05.htm>  
for the rest of jypsy's powerful statement to the  
Canadian Senate Standing Committee on Social  
Affairs, Science, and Technology

At 17 he graduated with honours in his mainstream class



# Discombobulation prevention

## Reduce occasions

- Change society [ha!]
- Make sure people get the support they need in order to keep their lives together
- Make space in the economy for people who are not multipurpose cogs for the great machine
- Persuade the labour market that monotropic benefits outweigh the down side
- what YOU can do is make the point in your neighbourhood

# Change the culture

Create awareness of

- autistic strengths - not the legendary autistic brilliance (the savant stuff) but the solid autistic virtues of dedication, accuracy, meticulousness, honesty, good will, determination, and reliability
- plus the individual - diverse, personal, idiosyncratic - characteristics which make autistics so much more different from each other than typical folk are, and thus so much more interesting

# What we can each do

- Start where we are, be active disseminators of positive information
- Make a website!
- Don't just make a website!
  - write something about our own sense of valuing our distinctive dispositions and those of other autistics we know
  - Print it out and give it to the people whose paths cross with ours. Have several copies ready.

# Sociable autistics

Let people know that

- although it *\*may\** take autistic children longer to become aware of a desire to interact with other people than it does most children, such a desire inevitably emerges.
- Not being well adjusted to other people's expectations does not equal not needing other people
- People need each other - we are that sort of animal - this tends to be even truer of autistic people because they are not receiving the typical range of social input and spontaneous mutual support.



Let people know that if you are  
“behaving badly” at some future time, it  
is NOT because you are

- Choosing to do so
- Wanting to do so
- Finding it amusing to do so
- NB Try to make sure the above list of NT assumptions does not become true - there really is no point in annoying people if we can help it

# Carving one's own niche

- This tends to be a slow process for monotropic people - mainly because society tends to harden against us every time we blow it
- We should get help identifying the right corners of social space which may welcome us
- We could volunteer to help those less able than ourselves

# Niche carving

- We should stop blowing it - sigh - every time we do, society hardens against us and we lose out
- We should work at **self-regulation** - we need to exploit biofeedback technology more fully
- We should work at getting people to understand us better - see above, all that positive stuff, but ALSO help them understand what to do when we do pop.

# Helping NTs understand

- What it's like to be autistic must include reasons for discombobulation
- Here is my short list:
- I realise I have misunderstood the situation - am blindsided but briefly
- I am misunderstood - again am blindsided, but it is harder to correct with longer recovery time and is sometimes worsened by a sense of insult
- I realise I have wasted all my efforts - probably through misunderstanding and am blindsided again, and furious with myself

# The discombobulation experience vis a vis other people

- For me people need to understand, usually:
  - This has no meaning even for me at the moment...
  - This is NOT ABOUT YOU! Please do not sit there attributing misattributing my emotions I will keep being unable to recover if you do
  - I don't need you to do anything but ignore this wave of dark feeling that has swept over me which I wish I could hide

# ....discombobulation recovery

- I do not want you to cluck meanings. I am not angry (or if I am it is with myself)
- I need time to recover spontaneously - this will happen if no further input worsens the state
- If I go away it does not mean I am avoiding talking about something you want to talk about; it means I am trying to recover enough to speak and listen

# Discombobulation prevention

- By chilling out [pre-emptive self-regulation]
  - finding a socially approved way of doing that is a really good idea
- eg dance, meditate, ride a bike or run a few miles, play with Reactive Colours ©  
<http://www.reactivecolours.org/>
- You thus both chill out and get social credit

# Tell the world

Autism does not need to be cured!

Autistic people need respect and friendship without having to turn themselves into hollow and exhausted simulacra of typical people

Fitting in requires acceptance and accommodation all round

People are being wasted, this can stop!



# Show the world!

Autism does not need to be cured!

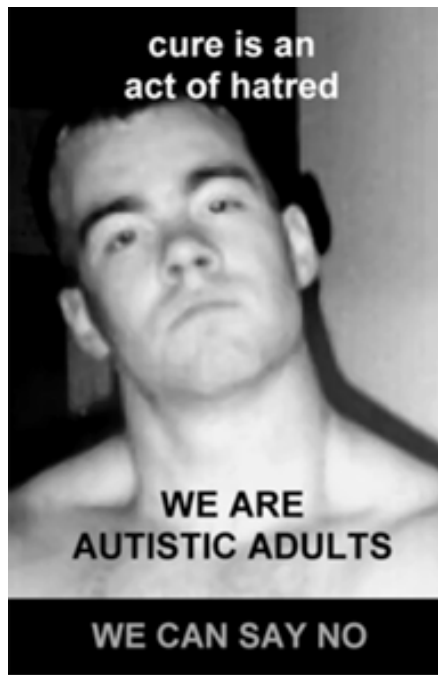
Autistic people make great friends

Monotropism can be a blessing both to  
monotropic people and to the world they live  
in...

Even if you can't find a job, you can

- Contribute your energies to local activist groups
- Volunteer to make friends with and empower an autistic person less able than you are

By artist,  
activist  
and  
autist,  
Ralph  
Smith  
See also



See also  
[http://www  
.sentex.net  
/~nexus23  
/art.html](http://www.sentex.net/~nexus23/art.html)

# Thank you!

- Autscape organisers for making it happen and having me along
- Sebastian Dern, Michelle Dawson, Wendy Lawson in advance, Dorit, Ilaria and Jim at the presentation, for various comments which I hope have made this the clearest and best thought out statement of our ideas yet (the remaining errors are of course not their fault!)
- Michelle Dawson, jypsy (Janet Norman-bain) and Ralph Smith for their encouragement to draw on their work in this presentation