

**Futures: Participation, voice and influence**  
 – Hearing the unvoiced  
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This talk will focus on issues in a research context

- *because research has an impact on real lives*
  - on media representations
  - on public perception
- *because autistics who do not speak are under-researched*
- *because the research community is a microcosm of the wider world*

How to improve social attitudes towards odd people

- fix communication issues
  - thus reducing the weirdness factor
- in the long term, over all shift of culture will result via media representations
- media representations will be affected by reported research (and perhaps by awareness of the recently announced Orwellian Prize for Journalistic Misrepresentation)
- research agenda and research conduct are therefore of central importance



A.M. Baggs

**Jamie Ponsonby cannot speak, and for years he was trapped in his own world.**

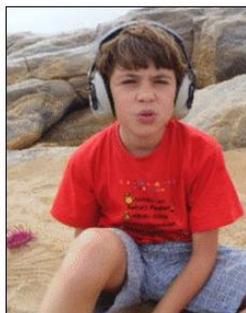
But his family taught him to type and now the 13-year-old, who has autism, can not only express himself, but also write poetry.

His mother, Serena, said this had enabled them to finally communicate with Jamie and to understand him better.

"We had no idea that there was a person in there who knew everything," she said.

**Humorous and emotional**

"Through the typing we have discovered he knows all sorts of things.



Jamie was locked in his world

- <http://news.bbc.co.uk/1/hi/health/10338131.stm>
- see [www.autismandcomputing.org.uk](http://www.autismandcomputing.org.uk) for many more similar stories

### Background research issues: pejorative interpretation is built in to a disease model

- the diagnostic criteria are normocentric and label the atypical as pathological
- research may need autistic scrutiny to ensure not just ethical, non harmful, research projects but also to clean up their interpretation
- research will benefit from **including autistic researchers**, not just from having a token autistic person on their ethics panel – though this would be a great start

### Widely held prejudices

- speech makes us human
- speech is correlated with mental capacity
- toilet training makes us human
- toilet training is correlated with mental capacity

### What may be going on for (very?) autistic people

- deeply attention-tunnelled (monotropic), contained interests – intensely aware of whatever they are aware of and tending to be unaware of everything else OR in an open non-focussed (non-assigned) state.
- even bodily functions such as hunger thirst and the need to excrete may not be felt; never mind subtler pressures from without.
- this slows down the making of connections between interests, but may speed up connections within interests.
- lifelong learning...

Sensory and other problems can occur in all modalities of communication:

Potential problems, especially but not exclusively, for autistic people	speech	writing	symbols / pictograms	computer
Phonology - sound processing	Red	Green	Green	Green
Intonation	Red	Green	Green	Green
Pragmatics – practical meaning	Red	Yellow	Yellow	Yellow
Semantics – logical meaning	Green	Green	Green	Green
Body language	Red	Green	Yellow	Green
Emotion-in/out	Red	Yellow	Green	Green
Motor coordination	Yellow	Red	Yellow	Red
Time pressure to respond	Red	Green	Yellow	Green
Auditory overload	Red	Green	Green	Green
Visual processing	Yellow	Yellow	Yellow	Red
Synchronised turn-taking	Red	Green	Green	Green
Rapid topic switching	Red	Yellow	Yellow	Yellow

■ Likely problem   
 ■ Possible problem   
 ■ Unlikely problem

### A different *modus operandi* not a less human being

see work by Michelle Dawson, Prof Morton Gernsbacher, Prof Mottron and colleagues re autistic intelligence and the pejorative slant of much interpretation (Akhtar & Gernsbacher, 2007; Dawson, Mottron, & Gernsbacher in press; Dawson, Soulieres, Gernsbacher, & Mottron, 2007; Gernsbacher, 2008; Gernsbacher, Dawson, & Mottron, 2006

see also the requirements of the Mental Capacity Act

### Getting consent

- “even when the capacity to give fully informed consent is questionable, obtaining meaningful assent from adults with mild to moderate mental retardation is feasible in nearly all cases.” - Fisher et al, 2006.163 (10) 1813...AmJ Psych
- NB their subjects were not autistic

## Research topic Number One

- How to achieve effective communication with people who don't speak?
  - they are being left out of the loop because of this issue: tiny amount of research compared with "HFA"; general tiny amount of involvement in the social world.
- Fisher et al speak of "individualisation"
  - similar conclusions about using *personalised* ICT are expressed in several of the papers in the recent Journal of Assistive Technology issue devoted to autism and IT (May 2010)

## involving autistic research participants takes time

- need to explain a lot, in a very clear, explicit and logical manner, preferably in a graphic form which can be revisited in the person's own time : then they can work it out
- work on communication issues with each person's support network
- keyboard access, Internet access
  - what is needed is patience, commitment, and time from support people
  - give people repeated opportunities (and means) to tell you what they think (as in the Access Project)
- A long lead-up time should be factored in

***If dealing with communication issues were common practice, all communications and two-way learning experiences would be more efficient***

## Participation via ICT including for non-speakers...

- people can be there with a skype presence
- people can create presentations using PowerPoint, designed for easy use
- people can use image to text or voice output software and send emails or chat, create blogs etc
- **people can use non-stigmatising iDevices**
  - *these are easy to personalise*

***All the above directly reduce the weirdness factor in the social equation***

## Research teams should ideally

- address communication issues from the start
- employ autistic researchers
- assume competency in research participants even if they do not use speech
- read autistic self-reports
- be aware of 'false consent' → "If I say Yes they will leave me alone sooner and I'll stay out of trouble..."
- understand spoon theory
- keep the pressure low

## Reporting research: a little useful language change?

- publish results widely and circumspectly
  - never talk about 'healthy controls' – *typical* perhaps
  - never talk about 'disease', *distinction* maybe (as in Not indistinguishable)? or *diffability* as Dr Lawson prefers, or *difference* as LARM proposes
  - never talk about 'subjects' – talk about *participants*

## main problems affecting the chance of attitude change?

the concept of diagnosis  
the diagnostic criteria  
the Insurance dependency of US services...

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