

Talk presented at Autism
Cymru May 10th 2006

Therapy and Justice

Therapy & Justice

*“The best form of therapy is justice” -
according to Valerie Sinasson*

This presentation is mainly about justice

It is about adults - *Autistic adults at every level of apparent ability* - and giving them a chance in a world which is rarely autism friendly.

My background

- Despite a PhD in linguistics, I have spent thousands of hours working at close quarters and one-to-one with autistic adults, many non-speakers, most known to have “challenging behaviours”. *Usually I have had a rattling good time.*
- You may think me an idealist, but I am at least not an ignorant idealist.

Evidence based conclusion

- When we achieve mutual communication we typically achieve mutual good will.
- Autistic people are well capable of being good team players, so long as they understand and see the point of the team's tasks, and can identify their own role. *This I have repeatedly found.*

Statement by an autistic adult:
(posted under the name 'Dustin' as
comment to www.gettingthetruthout.org)

- I am a 50 year old adult with so-called "high functioning" autism. I live in virtual isolation, even though I crave to have friends. I am on permanent disability, even though I could learn almost any job, no matter how technical. I have simply been exiled from today's "on the go" "multi-tasking" society - *This is a sadly typical case.*

- Justice is inclusion
- Justice is giving people a chance
- Justice is not wasting lives
- Justice is recognising autistic people as real human beings, potentially as able as anyone else to contribute to the common good

The Germans have coined a term, “ballastexistenz” for the lives of people whose personal value is nil - and who may be chucked overboard with impunity. I highly recommend ballastexistenz.autistics.org for amplification of this concept.

Autism not an illness...

These are just a sample of the voices raised on this issue. I think it's fair to say that most of the speakers at this conference have been known to express that view - and the evidence for it has been steadily mounting.

- Sinclair - Don't Mourn for Us (1993)
– web.syr.edu/~jisincla/dontmourn.htm
- Murray - Attention tunnelling and autism (1992)
- Happe - Autism: Cognitive deficit or cognitive style? (1999)
- www.autistics.org
- www.neurodiversity.com
- Murray, Lesser & Lawson - Attention, monotropism & the diagnostic criteria for Autism (2005)

Justice is seeing autism through unprejudiced eyes

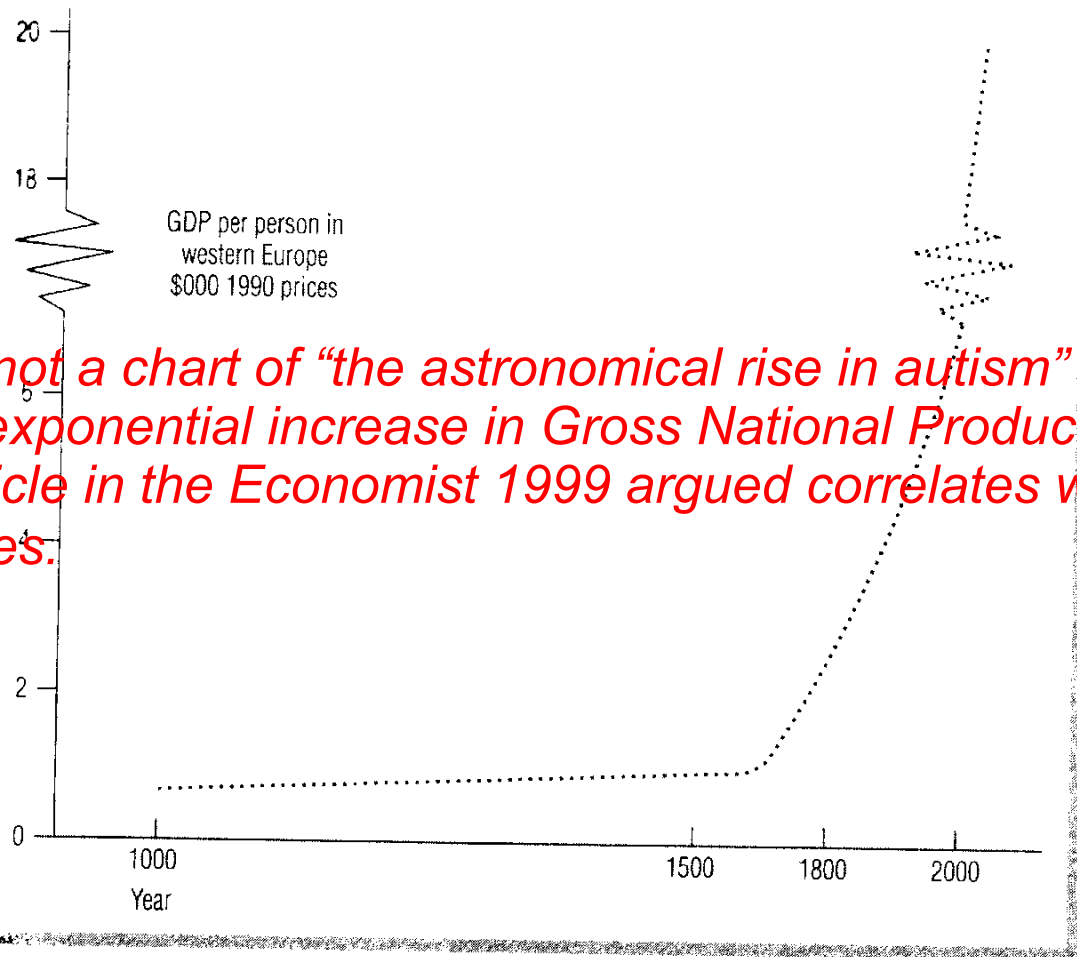
- Mottron, Dawson et al in Montreal (JADD 2006) and Gernsbacher 2005 (President of the American Psychological Association) (online presentation) demonstrate that research findings re Autism have been repeatedly interpreted negatively. *For example, these children are deemed dysfunctional because they take a long time to learn how to lie. We are supposed to be glad when our children tell lies!!* Results which differ from normal performance are seen as bad, even when, as frequently happens, autistic people show greater accuracy and speed than controls do. *The Canadians conclude it is appropriate to speak of :” Enhanced perceptual function” in autism.*

“Enhanced perception”

- No known illness improves performance
- Being normal/typical/neurotypical/NT is not exclusively a good thing (we knew that didn't we?
 - please see the flawed human beings of drama and religion...)

So - if it isn't an illness why has Autism become such a big issue?

up new ideas and changes that occur. Take a look at the graph from *The Economist*,³ (see Fig. 3.1), which shows the hundreds of years of almost repet-



No! this is not a chart of “the astronomical rise in autism” etc etc. It shows an exponential increase in Gross National Product which the original article in the Economist 1999 argued correlates with new ideas and changes.

Figure 3.1 ♦ The growing rate of growth and change

From *RELAX*, it's only *uncertainty*, a metaphor:

- ...an increasing level of global ambiguity (like global warming) has produced a rise in the sea levels of uncertainty. The inhabitants of the planet, having previously been accustomed to life on firm ground, now need to adapt to the more fluid environment in which they find themselves.
- Hodgson & White (2001) FT/Prentice Hall
 - *This a quote from the book which reproduces the table from the Economist you just saw.*
 - *Great title! Nobody likes limitless uncertainty, autistic people tend to find it distinctively difficult.*

Changes

- Higher levels of sensory variation
 - More rapid processing required at that level
- Higher levels of social variation
 - Fewer rituals
 - More strangers
 - Changeable performance expectations
- Over all less predictability, more uncertainty

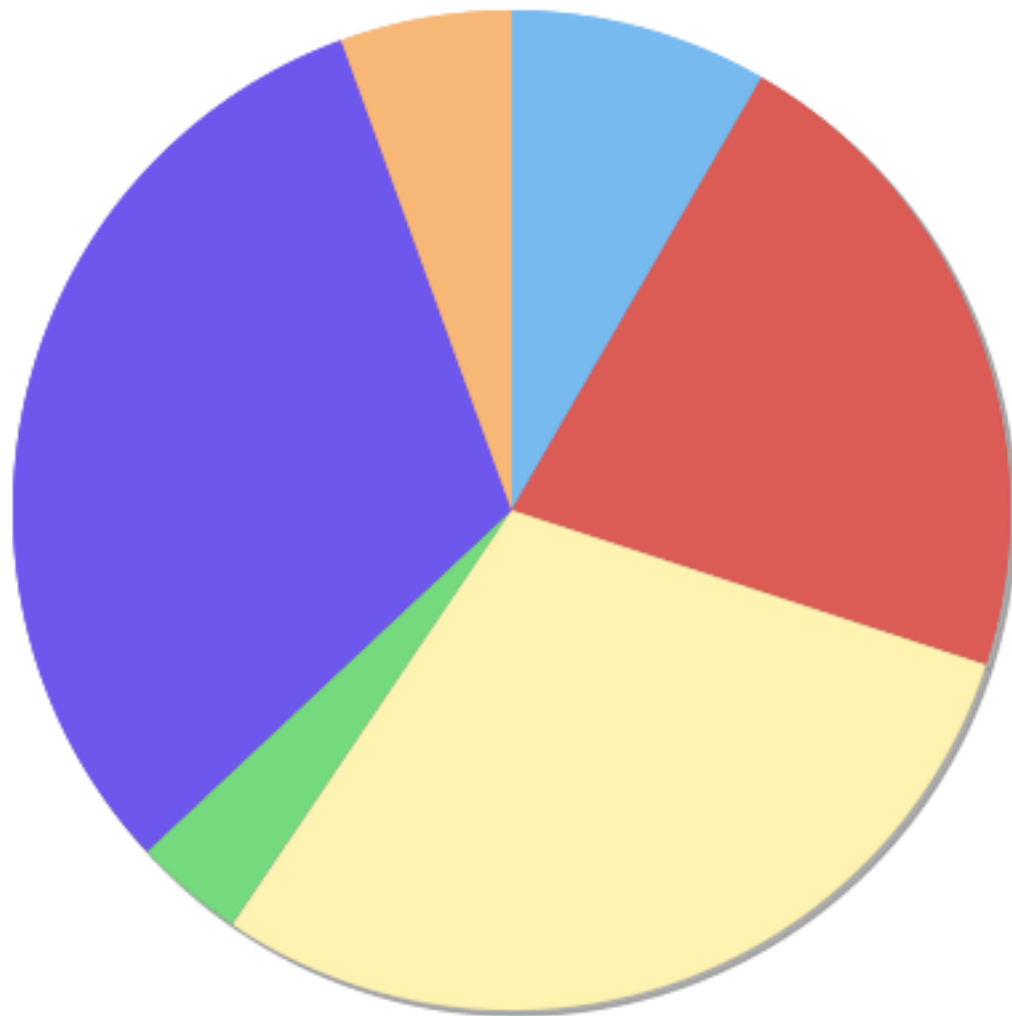
All of these can be distinctively challenging for autistic people

It's that "on the go multitasking" world that 'Dustin' describes...

One particularly significant area of change may be the labour market (statistics from the National Census):

The amount of information now online freely available from the National Census is phenomenal. This particular slice of it is courtesy of 'Vision of Britain' based at the Department of Geography of the University of Portsmouth

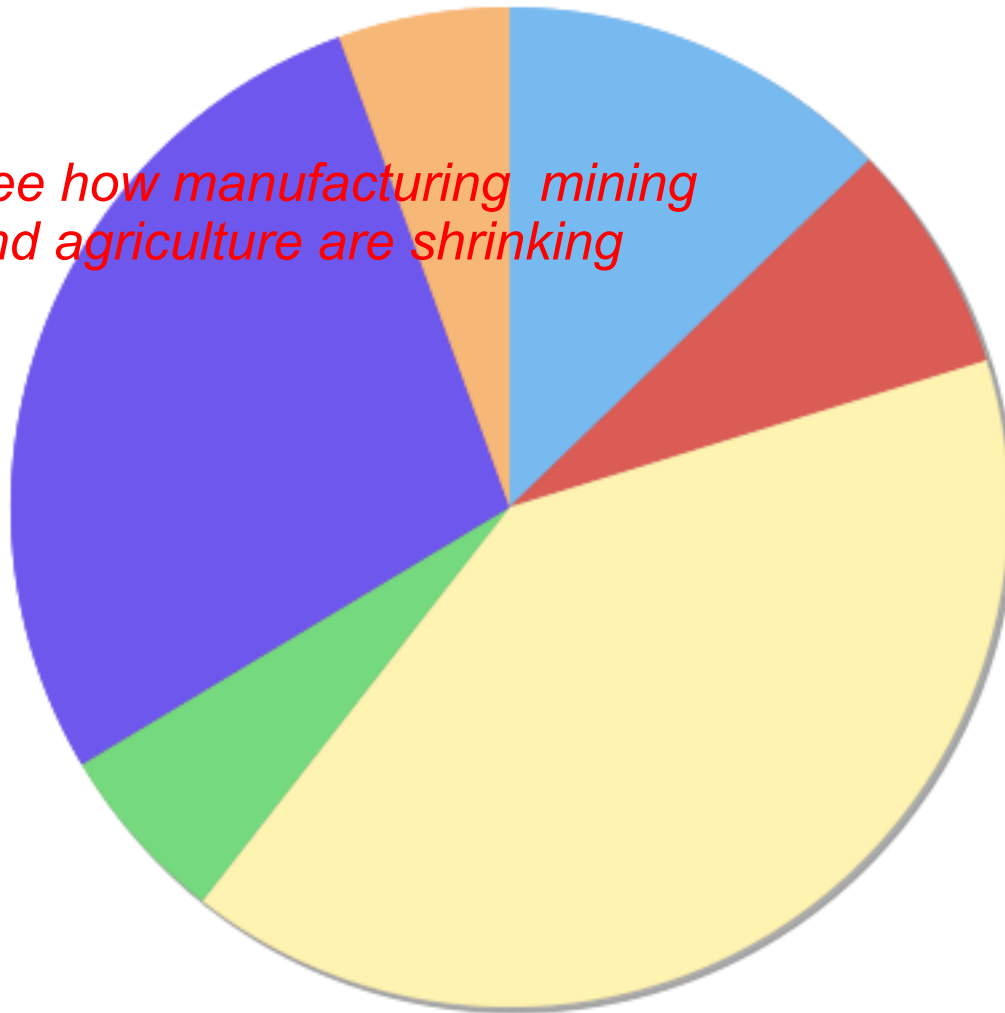
1841 labour market



- utilities
- agriculture
- service industry
- mining
- manufacturing
- construction

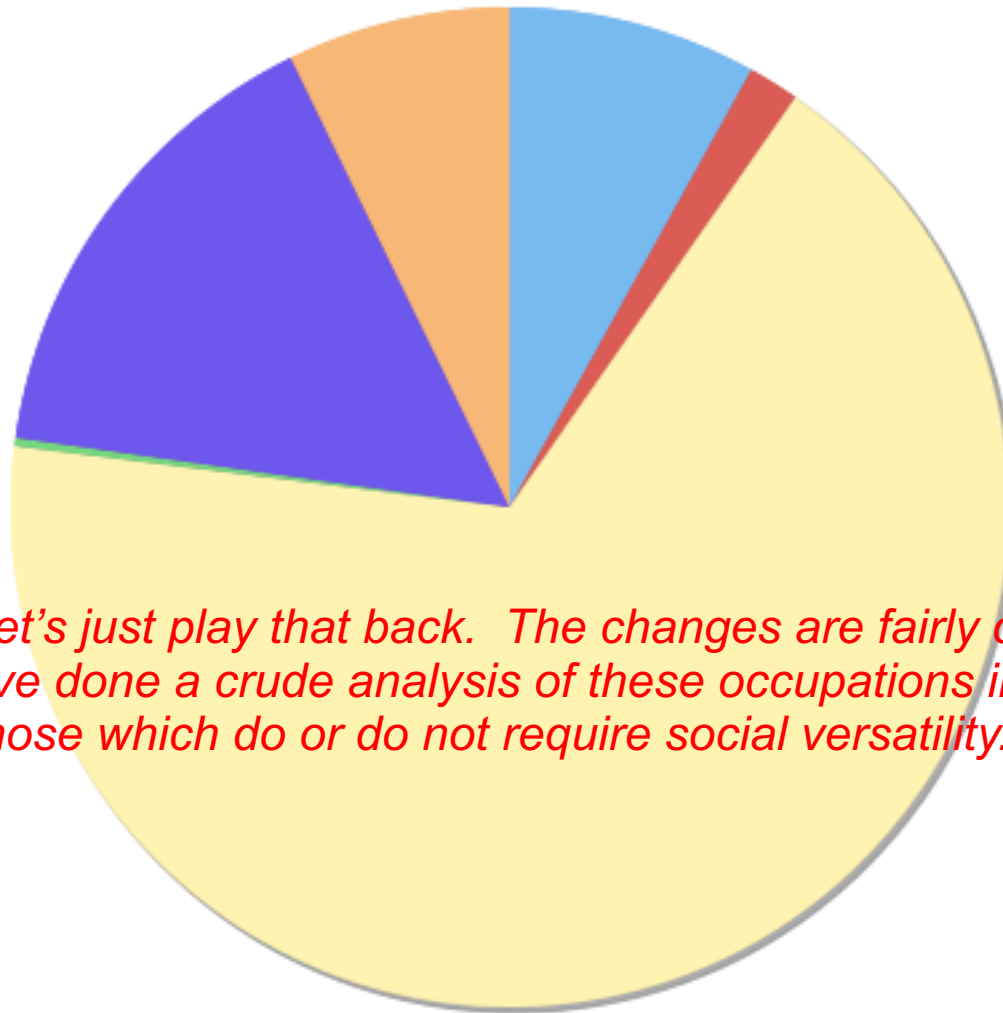
1931 labour market

*See how manufacturing mining
and agriculture are shrinking*



- utilities
- agriculture
- service industry
- mining
- manufacturing
- construction

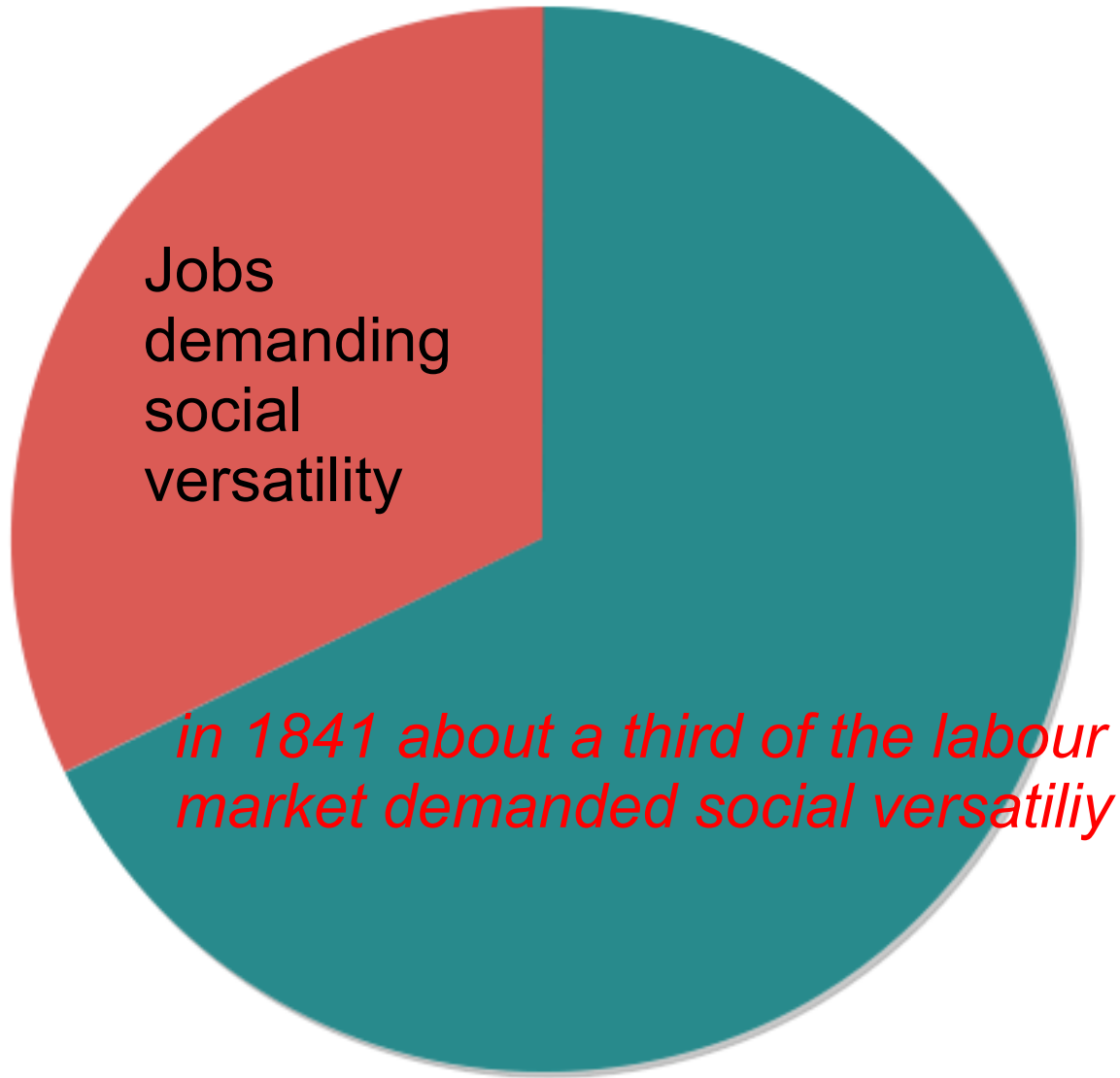
2001 labour market



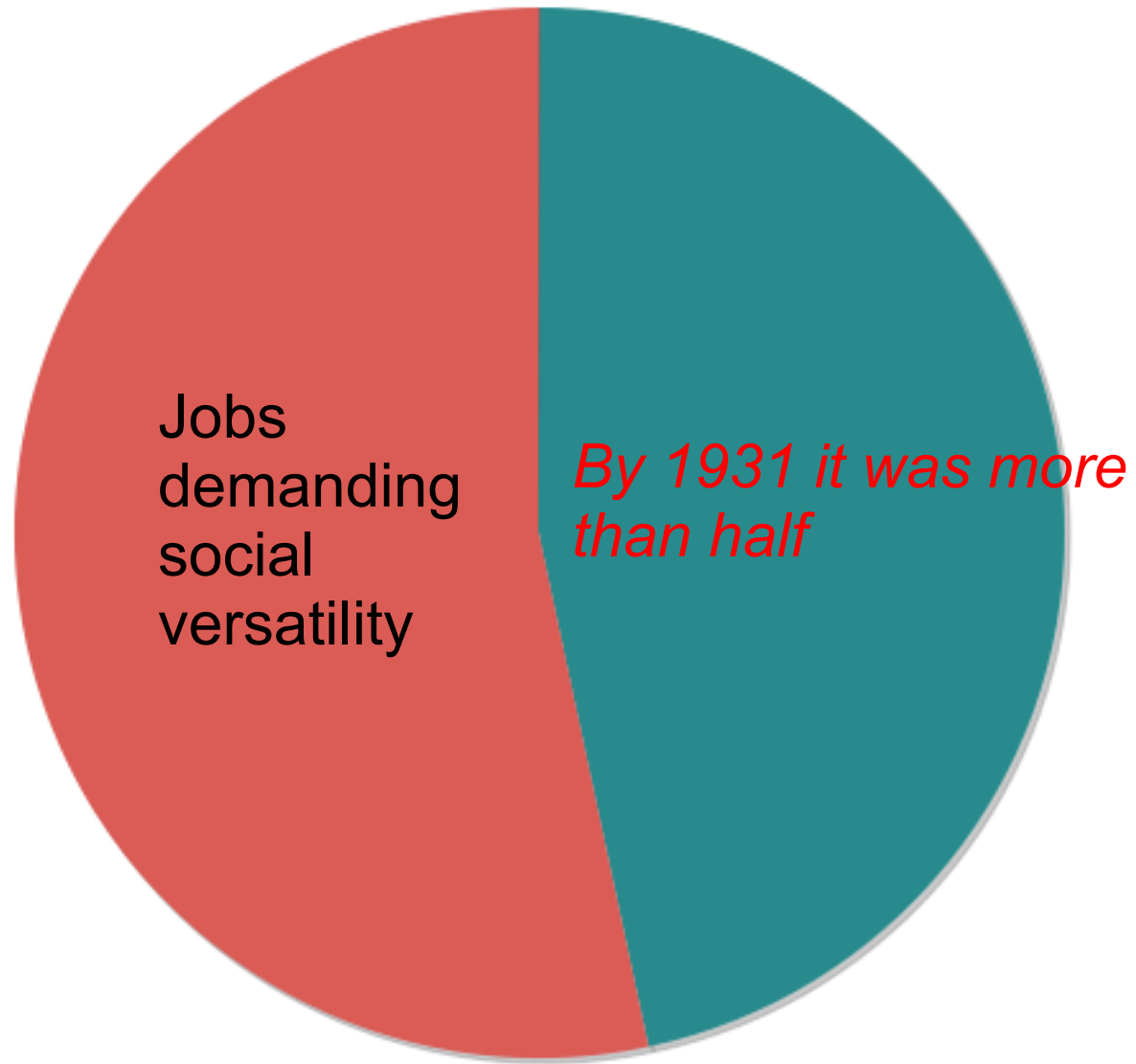
- utilities
- agriculture
- service industry
- mining
- manufacturing
- construction

Let's just play that back. The changes are fairly dramatic. I've done a crude analysis of these occupations into those which do or do not require social versatility.

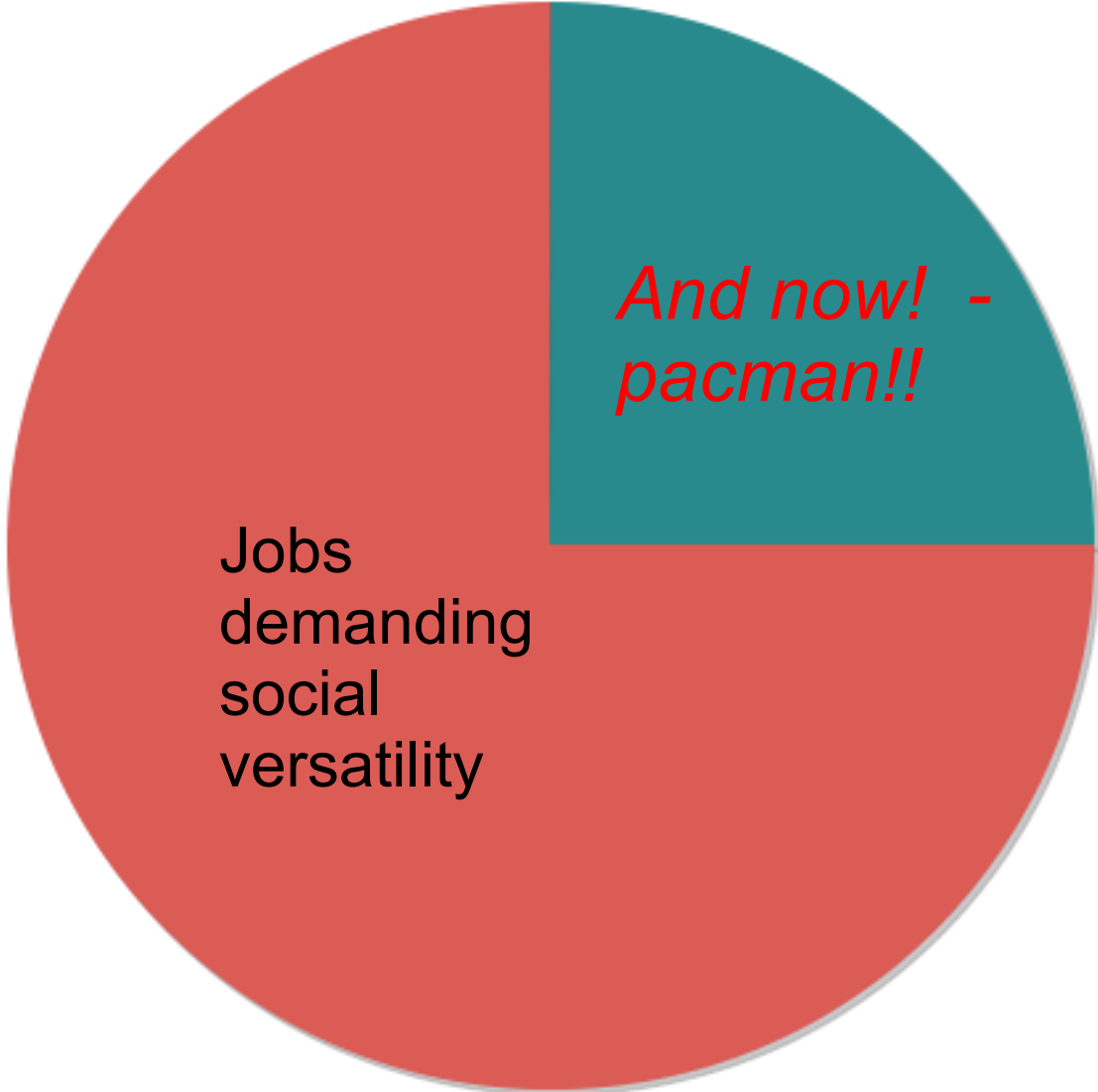
1841



1931



2001



It's even worse than that...

A cursory examination of job advertisements reveals that all but the most menial jobs in any sphere demand Teamwork and Communication skills.

Within most jobs workers will be expected to switch roles, take on unexpected duties, and carry out a variety of tasks.

We're meant to be multipurpose cogs these days - no more demarcation disputes!

At the present time it appears
that

Plus/minus social versatility =
Plus/minus social inclusion

I assume there is a correlation between unemployment and exclusion - we each need to find a niche, a place where we belong - having a job helps.

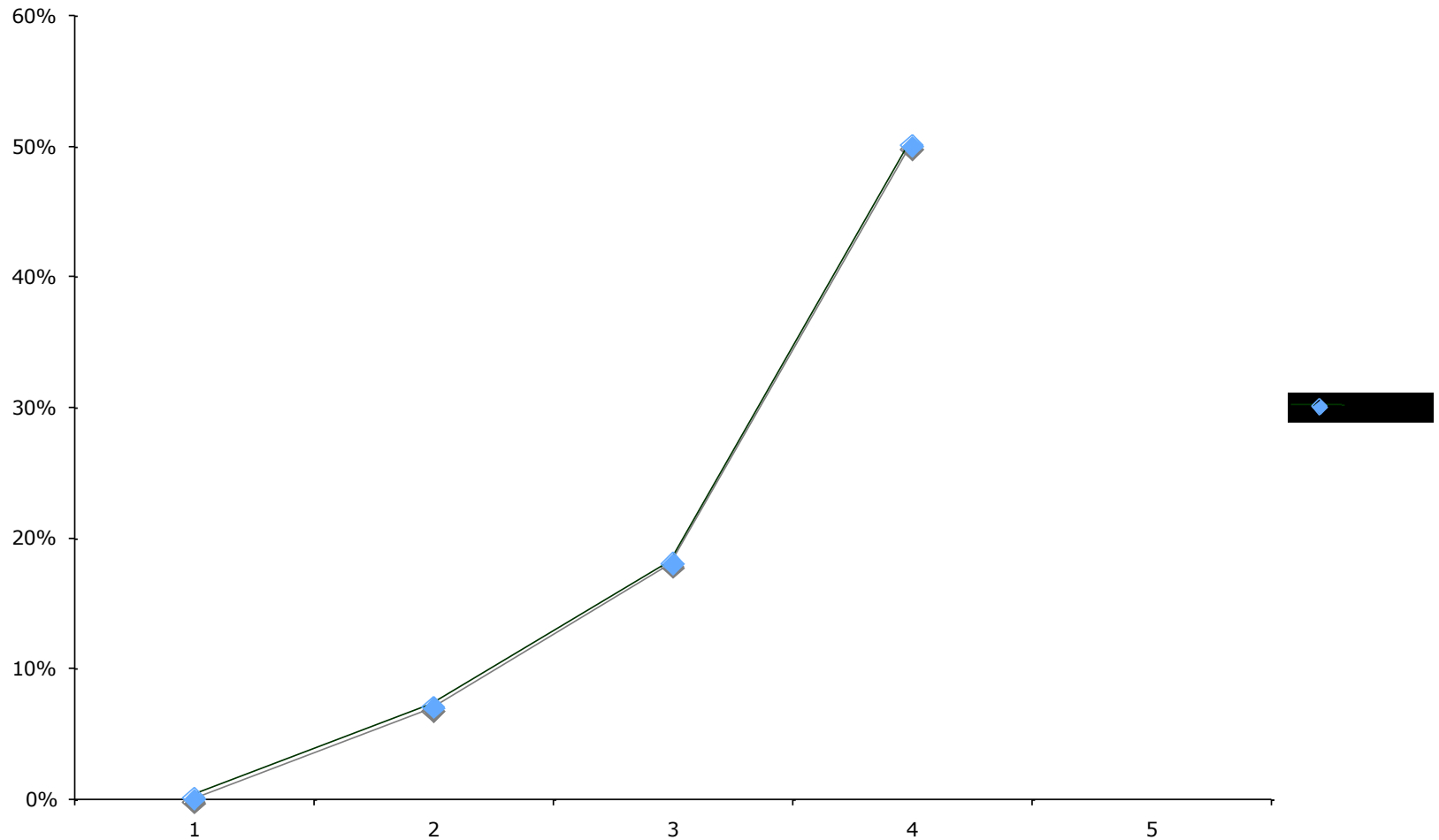
Is it all bad news for Autism?

No! *a tremendous autism friendly ecological niche has appeared in the last few decades*

One area of growth and change suits autistic people and has given them new opportunities for cultural and economic inclusion:

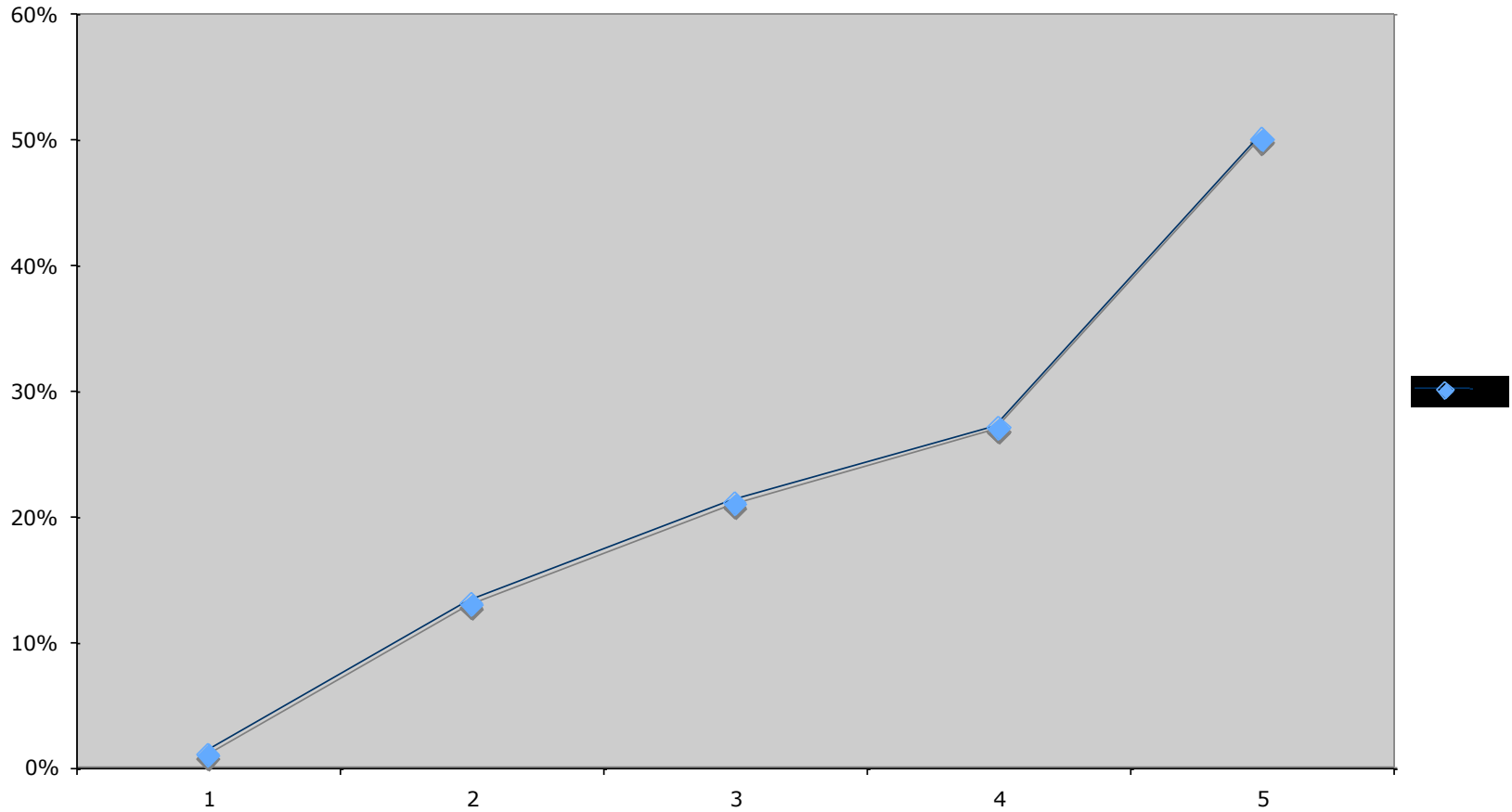
- Information Technology (IT) or Information & Communication Technology (ICT)

Web use in the USA from 1990-2001



Home computer ownership in the UK 1975-2001

%



Autistic self-advocacy on the Internet

A history of this lively movement can be found at

en.wikipedia.org/wiki/Autism_rights_movement

Jim Sinclair, Martijn Dekker and Janet Norman-Bain (jypsy) were in the forefront of Internet autism self advocacy which began in the early to mid 90s and is now worldwide and thriving.

This is a constantly growing field.

Why do these most recent changes suit autistic people?

- Familiar considerations about predictability and controllability with minimum extraneous information to absorb
- Because of these factors, I suggest, these changes can promote autistic social versatility and acceptance
 - In communication
 - In community inclusion
 - In the workplace

Communication

- A large proportion of autistic people find the pace, structure, and lack of extra social signals make electronic communication viable when other means of communicating (receptive or productive) are impossible.
- “X won't even communicate with autistics by email, the way most of us communicate best, this is like demanding that deaf people speak ‘right’ or that paraplegics climb the stairs” (personal communication from an autistic woman).
- Mutual understanding generates mutual good will.

Using the right - autism friendly - medium for communicating can get great results

Community

- Exclusion from the Internet is exclusion from the one realm in which autistic people are guaranteed a warm welcome (albeit not in every corner of it) .- *They are on a level playing field with everyone else, and they can be and often are very creative and communicative on line.*
- Communication by email can enable participation in local communities too. *I've just been involved in a neighbourhood campaign which was carried on almost exclusively by email.*

Workplace benefits

- With effective communication systems in place autistic workers will be able to participate and be as useful teamworkers as anyone else.
- Electronic media are effective all round.

In fact everyone can benefit from the advantages of email memo exchange etc, which is a self-recording medium, hence ideal for all bureaucratic processes.

European Charter for Autism

If you look at the European Charter for Autism (in the back of Opportunities and Solutions, Autism Cymru & PAPA) you will find that more than half of the rights listed will need access to IT in the 21st century.

Take a look!

<http://osiris.sunderland.ac.uk/autism/aeright2.htm>

(Contd from earlier quote) *This is more from Dustin.* - comment addressed to the author of www.gettingthetruthout.org

I wish that there was some way that I could talk to you. I don't have home internet service, or a usable computer. I could simply never afford such luxuries on my fixed disability income. Instead, I have to walk three miles to the public library, so that I can use one of their computers.

Here is who he was writing to...

This is the creator of www.gettingthetruthout.org



There are several pictures of her on the website; she took them of herself with a delayed shutter release. If anyone is in doubt about the authenticity of this site and its author

I can say that I have three independent reasons for believing the site is all it says it is - I have what they call 'triangulation' on it. It is real.

She is also an extraordinarily lucid and articulate writer with an acute analysis of her situation and that of those like her. She does not speak.

Getting the Truth Out



These are some of the things she has to use.

She uses this helmet because of severe self-injurious behavior in which she bangs her head with her hand.

Most parents don't anticipate buying diapers for this long, but this is often the reality with autism.

She uses the picture board because she cannot speak, but she won't always use it when she's supposed to.

It is awful for everyone around her when she gets sick or injured, because she can't tell anyone. People can only guess what is wrong from how violent or withdrawn she becomes.

Sometimes she screams, and nobody knows what she's thinking, but she's clearly frustrated about her communication disorder.

However, although all that is true, the fact is that these make her life manageable and give her some control over it - and **her computer and Internet access give her the power to reach out and communicate her experience and analytic insight.**

Justice

- Not dismissing people as non-persons because they do not speak, are incontinent, or self-injure
- Not condemning people as having “the seriously handicapping condition” eliminating which may be an aim of certain genetic studies.

How many of you have heard Wendy Lawson speak? or have read her books?

- Don't forget that Wendy Lawson did not speak for a year when she was about twelve. She might easily have never spoken again. Then you/we/the world would almost certainly have never known of nor have benefited from Wendy's intelligence and her good will.

Communication is the key

- The more severely communication disabled a person is, the more help they need.
- Getting assistive technology of every kind to people who do not speak is vital - and will pay for itself in reduced “challenging behaviours”

Two practical workers in the UK who have demonstrated the value of IT for adults with severe communication issues:

- Ann Aspinall, Home Farms Trust

Ann.aspinall@hft.org.uk

- Lynsey Way, focus communication and behaviour support

lynseyway@fsmail.net

Feel free to contact either of them to find out more.

Justice

- Ensuring that people can access needed assistive communication, (including computers and the internet like everyone else) is the single most useful step Government can take.
- Communication enables participation.

Which the Government says it is very keen on!

Justice & Therapy

- Enabling communication and promoting social participation are goals of all worthwhile autism “therapies”.
- That is how therapy and justice overlap in autism.

What Government bodies are concerned?

- Disability Rights Commission
- Equality Commission
- Making Decisions
- Learning & Skills Council

- According to the Home Office “Promoting equality and diversity is a duty the entire UK government take very seriously.”
- Failure to ensure access to assistive/electronic communication should be seen as discriminatory vis-à-vis people with Autism Spectrum Diagnoses in the workplace - *or for example in a Tribunal situation.*
- Refusal to employ someone because they have communication issues should be seen as discriminatory.

Contact

equality.diversity@dfes.gsi.gov.uk

And/or the Disability Rights Commission
at independentlivingbill@drc-gb.org or
Caroline.Ellis@drc-gb.org

The DRC is finally focussing on learning disabilities, autism and Asperger Syndrome.

Mental Capacity legislation

- *All practicable steps must be taken to help the person to make a decision for him/herself. This includes providing all information relevant to the decision in question in a way the particular individual can understand. It is important to choose the means of communication that is easiest and most appropriate for the person concerned. (3.35; proposed Code of Practice our emphasis)*

*This is REALLY important since it applies to every act of every support worker supporting every decision - it is about the **principles** of assisting choice.*

Concerns re the Mental Capacity Guidelines

Although the guidelines are generally well thought out:

- The advice appears indifferent to the (inclusive) role of computers and information and communication technology in the Twenty First Century.
- The advice fails to recognise the potential of computers to enhance decision making capacity for people with communication challenges.
- Insofar as the advice fails to emphasise the key importance of access to ICT, it risks compounding the social exclusion of an already excluded group.

They favour signs and 'widgets' (I'm not against these, but they are closed systems in themselves). Signs and widgets can of course be accessed via computers, but the guidelines do not recommend this. To me this raises a question about the sincerity of the splendid things they say about remembering not to judge people on appearances and remembering people can go on learning all life long, and so on...

Contact

makingdecisions@dca.gsi.gov.uk

OR

eddiecoleman@dca.gsi.gvo.uk

They are actively soliciting feedback.

Note of Warning

- Not for everyone!
- ICT needs to be an option, not a hurdle
- Some people hate the idea - pressing them could be counterproductive.

And of course this is not about replacing real people.

Some Good News:

The deadline for feedback re Mental Capacity Code of Practice is May 31st.

If you go to www.autismandcomputing.org.uk you will find this presentation with hyperlinks to all URLs and email addresses cited.

The LSC has abolished the 25 years cut-off point for funding students with learning disabilities.

The LSC has introduced RARPA - Recognition and Recording of Progress and Achievement - which recognises IT skills.

Getting IT - using information technology to empower people with communication difficulties by Dinah Murray and Ann Aspinall, Jessica Kingsley (2006)