

‘If people do care why is change so slow?’

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Why that title?

- I am giving opinions here based on my experiences and learning in multiple roles not claiming to give definitive answers
- I will set out my reasons for thinking people do care
- I will set out why I think things are overall improving but far from uniformly and not without slips and backward steps along the way
- I will set out why I think it is slow and explore some of the barriers and some potential solutions – the focus in my talk is on England
- NB this is a brief overview so I cannot cover all the factors that reduce quality of life for autistic people but everything I say should be seen in the context that intersectionality of all types does lead to poorer service offers which needs to stop if outcomes are to improve

Do people care?

- Yes – not all but increasingly large numbers
- The range of publications on or about autism has hugely risen in last 25 years – research, mainstream media, online
- Many more people are now identified as autistic in all parts of society
- Training courses of multiple types are out there – yes some mandatory so risk of tick box attendance (so don't indicate they care) but some information will hopefully still get through but also in courses people opt to go on e.g. The HEE “Autism Essentials for Psychiatrists” courses in 2019-21 attracted over 1500 psychiatrists (and over 600 people who were not psychiatrists)

Are things improving?

- The large increase in articles, research, talks, media of all types reflecting the interest and broadening the evidence base
- Having an interest or going to a training course does not mean anything magically improves
- The Autism Act 2009 made it mandatory for all Clinical Commissioning Groups (as they were then now replaced by Integrated Care Boards) to have an autism diagnostic pathway
- Numbers accessing those pathways since then have massively increased even though it is very patchy, capacity does not match demand and long waits are common. As one example Wirral 2012-3 9 adults assessed now routinely 130 adults assessed per year ie a 14 fold increase and similar across most of the country

Are things improving

- To deliver these extra assessments required more staff training and staff becoming much more experienced in the different ways autistic people can present so increasing local knowledge and expertise
- Majority of people who are diagnosed autistic report this to be positive and helpful outcome – around 80% is a common figure and many more are being diagnosed each year
- National mandatory training (Oliver McGowan Mandatory Training) being rolled out to give all health and social care staff information about autism
- Multiple voluntary and community groups – some autism specific, some autism aware and welcoming

Are things Improving?

- New English national strategy
<https://www.gov.uk/government/publications/national-strategy-for-autistic-children-youth-people-and-adults-2021-to-2026>
- Autism champions, autism hubs, autism teams of various types now exist in patches

Are things Improving?

- The need to deliver “reasonable adjustments” now well known and more commonly applied (but well short of routine)
- More opportunities and platforms for autistic experts by experience including in service planning and delivery

Why is change so slow?

- Myths and legends take longer to dispel than just attending a training course
- Training tends to reflect what was known at time it was written and in fast changing field some of it out of date very quickly. What was considered best evidence training 20 years ago would be multiply wrong now.
- Human factors mean people tend to hold onto what they were first taught and interpret new things on that basis
- The use of terms such as Autism Spectrum Disorder or Autism Spectrum Condition persisting rather than use of Autism as per 2009 ACT
- Not moving from impairment based language and reporting to using strengths, needs and aspirations model

Why is change so slow

- In late 20th century the stereotypical expectation of autism was a boy with learning disability
- As late as 2014 national bodies still referring to over half autistic people having learning disability. Current figure is 20%. Some studies suggest lower still. NB that 20% are a highly vulnerable sub-group e.g. account for over 50% of restraints in one trust audit. They must not become further marginalised
- If you only expect to see autism in males with learning disability then you are very likely to miss a lot of it and sadly this has been the case – people have been refused referrals for assessment due to not being male, not being a child, not having learning disability, not “looking autistic”. Even some people with confirmed specialist diagnoses have been told by health and social care services they can’t be autistic for above type reasons

Why is change so slow?

- Despite vast majority of autistic people not having a learning disability they are often required to go to learning disability services and/or given information designed for people with learning disabilities which is clearly not appropriate or person centred care
- Autism is neither a Learning Disability nor a Mental Illness it is a neurodiversity – but autistic people do have higher rates of multiple physical and mental disorders but face much higher barriers getting access to services and even if they get through too often get told “we can’t help as we can’t treat autism” when what is needed is treatment of the physical or mental disorder (Diagnostic overshadowing costs lives)

Why is change so slow

- Services “person blaming” “you have communication difficulties” rather than “between us we seem to be having some communication problems how can we address that better”
- Some training sets such an impossible expectations that services can’t reach it so give up and don’t try – “reasonable adjustments” have to be reasonable
- Some training implies that all autistic people need the same adjustments – for some people a brightly lit room is a problem, for others a dimly lit room is a problem. “Blanket reasonable adjustments” are a restrictive practice. They must be person centred. Listen to the person (including advance directive/hospital passport) and to those who know them best

Why is change so slow?

- There is still little research – more in childhood, less in adults and virtually nothing in older adults. Autism is lifelong and most autistic people will live well into their late 60s and beyond (even with the high premature mortality rate). Even prevalence rate shows high variation depending on methods used
- Stigma – still exists and although in many ways starting to reduce in others it is getting worse
- Fear of getting it wrong – autistic people have always worked in and attended services but were not identified as autistic (and most still are not) but staff say we can't treat autistic people because we lack the skills etc. The skills required are those to treat the physical or mental disorder not autism
- Erroneous fashion pushing PBS (Positive Behavioural Support)

@BreneBrown

“
We need to dispel the myth
that **empathy** is ‘walking in
someone else’s shoes.’ Rather
than walking in your shoes, I
need to learn how to listen to
the story you tell about what it’s
like in your shoes *and* **believe**
you even when it doesn’t
match my experiences.”

Why is change so slow

- Failure to make best use of available data. In England NHSD has produced a monthly report since 2015 on people with learning disability (LD) or who are autistic in MH or LD inpatient beds of any type.
- They report two different data collections AT (Assuring Transformation) and MHSDS (Mental Health Service Data Set)
- At present AT is the set which is reported more widely and influences policy, national thinking etc. It does not reflect the reality of inpatient admissions but collects data on a sub-set which is low volume, high cost, low turnover.

Comparison of AT versus MHSDS data April 2022

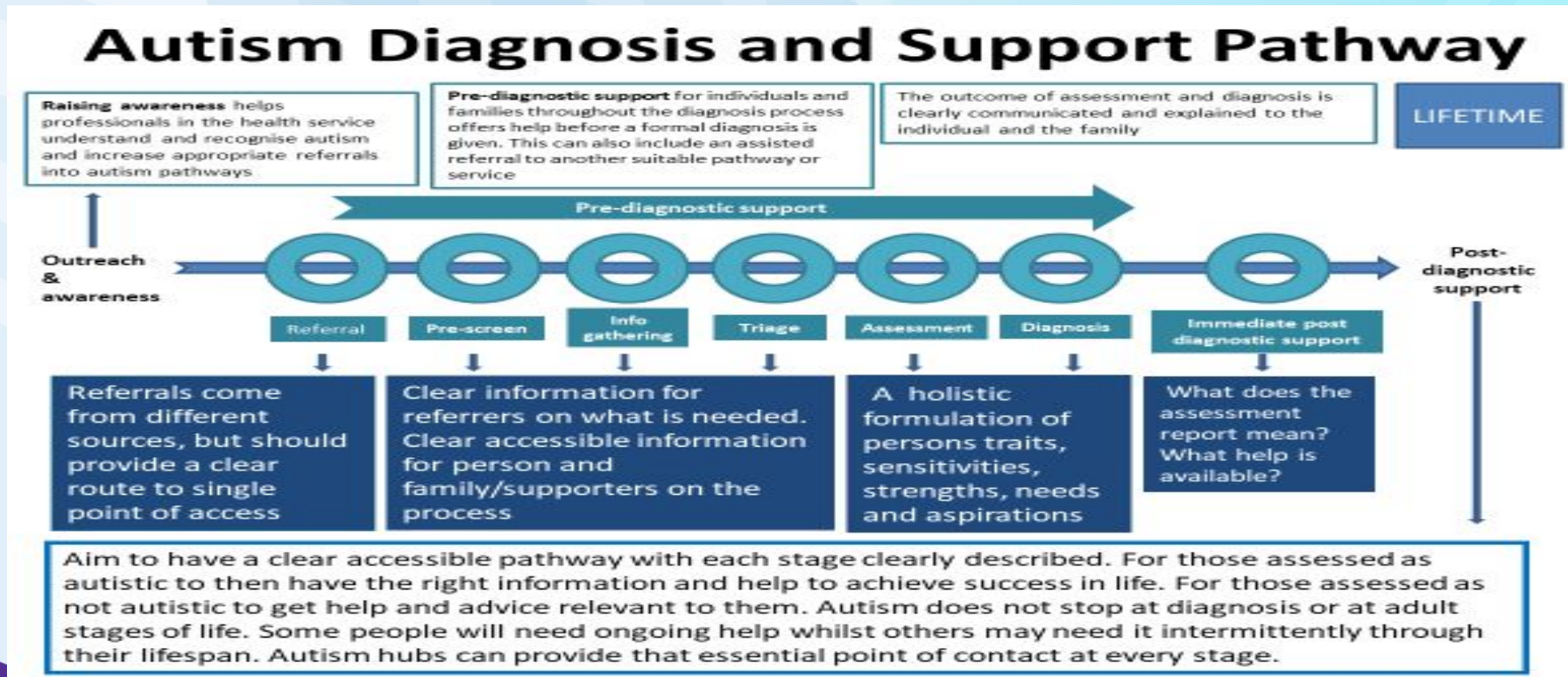
Comparison of AT and MHSDS data

April 2022	Inpatients month end	Admissions in month	Discharges in month	Lengths of stay over 2 years
AT (Assuring Transformation)	2000	70	130	1135 (57%)
MHSDS (Mental Health Services Data Set)	3590	1025	1135	1380 (38%)

Do data collection and reporting differences matter

- Whilst numbers of very long stay (over 2 years) are similar admission and discharges differ significantly i.e. AT does not reflect those with shorter lengths of stay. In the MHSDS data set 365 (36%) were admitted and discharged in same month.
- Looking at a 1 year sample of people admitted with autism recorded as one of their diagnoses in CWP adult/older adult MH services the average length of stay was actually shorter (non-significant variation) than for those without an autism diagnosis
- You can't plan and deliver effective services using the wrong data so it is essential that MHSDS data is used and analysed as it is much more accurate in terms of activity and data quality can be further improved as part of general work improving MHSDS data quality

Lifelong model



Training without real-time accessible advice and information has little impact

- Useful options for getting that information
- NB the person/family are experts on the person's autism ask what is known to be helpful – do not apply blanket “reasonable adjustments” from some course - needs to be person and situation centred
- Autism Hubs
- Local Autism Champions (with lived experience of working in and delivering the MH service)
- Regional/sub-regional autism teams offering specialist advice, consultation and liaison
- Checklists/aide memoires that are easy to read in urgent situation or busy setting
- Easily accessible online information specific to that service
- More generic autism online information to top up knowledge

If an autistic person is in distress or crisis

C**COMMUNICATION**

Check if the person can communicate what is wrong?

Are there any communication needs you need to be aware of?

Are you communicating effectively?

Do you need to adapt how you communicate with the person?

H**HEALTH**

Check the person's physical and mental health.

Are there physical health issues affecting their presentation?

Are they in pain?

Is there an underlying mental illness?

E**ENVIRONMENT**

Check the physical and sensory environment.

Ask the person about their sensory preferences and sensitivities.

Is it too noisy, busy or too bright?

Is the person sensitive to touch?

Can you make changes to minimise distress?

C**CHANGE**

Check if there have been any significant or unexpected changes or a build up of small changes in the person's life or routine?

Ask the person and if possible, someone who knows them well what may have caused the distress, what helps in crisis and what are the person's preferences.

K**KNOWLEDGE**

Know the person: Check what is normal for the person.

Are there any co-occurring conditions?

What treatments are they on?

Is there an Informant, a Hospital Passport or Advanced Directive?

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If someone has enough self esteem and confidence they can clarify information, ask for reasonable adjustments and ask for help when they need it



One of the biggest impacts health professionals can have is to support someone to recognise their strengths and work to achieve their aspirations

Background reading on recognition, reasonable adjustments, barriers to healthcare (all open access)

- <https://www.magonlinelibrary.com/doi/full/10.12968/hmed.2021.0313>
- <https://www.magonlinelibrary.com/doi/full/10.12968/hmed.2021.0314>
- <https://bmjopen.bmj.com/content/12/2/e056904>
- International Journal of Positive Behavioural Support, Volume 12, Supplement 1 Positive Behavioural Support in the UK: A state of the nation report – contains why PBS not suitable for autistic people who do not have Learning (Intellectual) Disability

Key legislation and guidance

- England The Autism Act 2009
- <https://skillsforhealth.org.uk/wp-content/uploads/2020/11/Autism-Capabilities-Framework-Oct-2019.pdf>
- <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>
- Equality Act 2020
<https://www.legislation.gov.uk/ukpga/2010/15/contents>
- Mental Health Act (and proposed amendments)