

GMAC / NAS Conference
Post Diagnosis Care / Support
Weds 2nd October 2019
Friends Meeting House, Manchester

Presentation

1. Title slide

Apologies for lack of pretty slides. The alligators would not allow me to drain this particular swamp. : >

2. Peter Baimbridge – for those who don't know me, am I

- a. Pragmatic, autistic, 63yo adult male
- b. Divorced, 1x daughter
- c. career in technical sales, marketing and business management
- d. measured IQ 150
- e. 30+yrs in and out of MH with no useful diagnosis
- f. AS/HFA diagnosis 56yo
- g. Started Salford autism 7yrs ago in response to lack of appropriate services for higher functioning adults
- h. Doing what I can to help those who want / need it
- i. Sit on:
 - i. GM, Manchester, and Salford Autism Strategy Boards
 - ii. GMP Advisory Board
 - iii. Regional and National NHSE advisory boards
- j. Coordinator Autism@Manchester, UoM.
- k. Present on autism to UoM Clinical Psychology course
- l. Deliver autism training to wide range of organisations e.g. TMC, Pennine Care, Salford University, CMHTS, HITs, hospital departments, charities, and the general public.
- m. Links with autism activist organisations around the UK
- n. Regular speaker to autism conferences and local groups

3. Salfordautism

- a. brief history / why we exist
- b. what we do
- c. where we operate
- d. Difficult to discuss a specific 'service' as we are not a 'service provider' per se
- e. We are a **solution provider** – different matter entirely!
- f. We deliver holistic solutions to real life problems identified / experience by autistic people or those associated with them.
- g. We are not interested in the existence or otherwise of any particular diagnosis, as anyone who is not really autistic soon filters themselves out and goes elsewhere.
Our knowledge of autism is only used as an advisory to what we do.
- h. We do not work to a 'service spec.' We work to *outcomes achieved* and a set of guiding principles / beliefs
- i. As some of you will already know, we continue to be unfunded, so work with a skeleton staff, but we respond to every call for our help and will get involved wherever we can be effective, or we find someone else who can and will do better.
- j. While we are mainly Salford-facing, we are getting called on more and more across the GM footprint, by GPs, adult and childrens services, diagnosticians, CMHTs, HBTT, schools, education authorities, police, prisons and probation services - as well as autistic individuals and families in crisis.
- k. Our contact line is used by autistics in need as far away as Glasgow, Hull, Norwich, London.
- l. Our drop-in in Eccles is accessed by autistic adults, parents of autistic children and others from as far away as Stoke on Trent and Preston.

4. THE WORDS YOU USE ARE SURPRISINGLY POWERFUL – use them sparingly and accurately, especially around autistic people.

5. We work to the 'social model of autism and have serious concerns about the medicalisation of what is a naturally occurring condition and part of the human genome.

We are especially concerned when the (overly complex) medical view of autism is delivered to those who get diagnosed as 'this is how you are / should be', and, being autistic, they feel they should act up to what they

have been told autism is, rather than using the information to understand their own, specific, pre-existing difficulties.

As an organisation, we do not address anyone's diagnosis in any way, but may use it to inform how we address real world problems that beset them.

No-one can change someone's autism! The only way forward is to change how the world treats (autistic) people and teach the autistic person better skills to deal with the world as it is.

6. The more is understood about autism

a. the higher our perceived prevalence rates climb

From our experience of the range of autistic people we work with (NB: we have no preconceptions and we do not filter who comes to us) and where we find them, we feel that prevalence rates may well eventually set out c. 5-6% of population

b. the higher the proportion of non-LD autistics are found

It is currently accepted that well over half of all autistics do not have a learning disability

Our experience suggests that 75-80% of all autistics beign without LD is about where it will eventually settle out.

c. the higher the proportion of adults to children are found

Autistic Children do not suddenly cease to exist, or to be autistic, when they hit 18 - so they grow up to be autistic adults – who have *always* been with us.

It is currently accepted that there are 3-4 autistic adults to every autistic child. There may be more, but undiagnosed / incorrectly diagnosed.

7. Autism - Not a 'disorder', but a *condition*

- Most of us are not 'broken' or 'dysfunctional'
- Most of are just 'different' from most of everyone else, and so may need a hand, on occasion, to deal with the problems that beset us, most of which are actually caused by others who are not autistic.

Nobody would call pregnancy or menopause 'disorders'

8. Umbrella concept of Autism

Too many of our clients exhibit too many different characteristics of different 'autisms', depending on circumstances, longevity and depth of observation.

9. “Neither a learning disability nor a mental health issue” – HMG, Autism Act, Statutory Guidance,

When are health and social care services going to catch up?

All too often we hear MH service say things along the lines of “Oh, yes, we know, all about autism! We’ve had autistic patients in here before. We’ll deal with the (psychosis) first, and the autism later”

Autism is by definition:

- *pervasive* i.e. affects everything. One cannot ‘treat’ anything without going through their autism!!!
- *developmental* i.e. it affects everything they have become
- *lifelong* - you’re born with it, you die with it! Simple!

There is no cure.

There is no treatment.

While some manifestations may sometimes be helped with drugs, there always seems to be a price to pay.

We believe that we can all learn skills, that we can employ when we choose, to help us deal with the non-autistic world

There is no such thing as an autistic person that cannot learn – given the right teacher

We do not need to change.

10. We do not like the term ‘Diagnosis’

- a. implies *disease* + *treatment* / *cure*
- b. prefer (formal) ‘assessment’ / ‘identification’
- c. only useful if used as a key to delivering appropriate support

11. We do not like, the term “Post-Diagnostic Support”!

- a. We prefer “Good Customer service”!
 - i. should start:
 - as soon as ‘autism’ starts to be considered
 - before the ‘A’ word is mentioned to client
 - ii. should consider the effect of using ‘the word’ around an individual and the ongoing effect of not getting formal diagnosis for some time
- b. If we must have a trite phrase / title, we would prefer

“Peri-Assessment Care” i.e. care taken or given, leading up to, through and after assessment, but related to it, rather than subsequent or specific issues or ongoing maintenance.

12. Focus on what someone *can* do, not what they cannot

We all have something we are great at, and something we are crap at.

Ditto every NT and autistic person alive.

Work towards someone's *abilities*, not their disabilities

All support should have a strong element of enablement, and never assume *any* disability is 'fixed'

13. Although we are not Learning Disabilities specialists, we are not convinced that 'Learning Disabilities' is either sufficiently well understood, or appropriate nomenclature.

Every time we get involved with 'learning disability' groups or people, we are amazed by just what some of these so-called 'disabled' people actually can do and understand - if presented appropriately.

14. What we do offer that fits around an individual's assessment is:

- a. Someone with lived experience to talk to about what autism might mean to them personally, the implications of applying for assessment, and either getting a diagnosis, or not – at a time and place convenient / comfortable to them
- b. Transport to and from assessment centre, for those who might find it too difficult otherwise, escorted by someone with lived experience, who can talk them through the process, ensure they arrive as relaxed and prepared as possible, give moral support through the interview (if wished) and a debrief on the way home
- c. 24/7 contact line, connecting anyone who has either a problem or a query around autism with someone with lived experience, who can and will help – if only by talking through whatever the caller wishes to know about.

If necessary, and there is something we can do (better than someone else), we will turn out, 24/7.

- d. As many 1-2-1 times as the individual needs / requires to help them get their head around what they have just discovered about themselves
- e. Support to help friends, families, employers, and whoever else, understand and be able to support the individual around their newly identified condition
- f. Specialist autism advocacy services to help autistic individuals:

- i. convey what they wish to others, and understand what others say
 - ii. successfully address conflicts / disagreements etc. with others e.g. employers, landlords, DWP
 - iii. representations at meetings, discussions etc., from (all types of) assessment interviews up to High Court attendance
- g. social inclusion / relevance
- i. to help them understand themselves
 - ii. to help them develop useful communication tools and experience
 - iii. to provide them with useful and appropriate social environments for their own comfort and wellbeing
 - iv. to make sure they know that they and their company are valued and that someone does give a damn about how their life is going.
- NB: *everyone* needs a hug from time to time, someone they click with to hang out with, intimate relationships, someone to ring when they are down or in trouble – even autistics – we just need it ‘in our own time, in our own space, on our own terms’

15. Word for the day: “TAKIWATANGA” – Maori for ‘autism’

Literal translation = ‘in his own time, in his own space’