

#### **Kent Academic Repository**

Milton, Damian and Mills, Richard (2018) 10 rules to ensure autistic people obtain poor mental health support...and maybe what to do about it. In: Scottish Autism 50th Anniversary Conference: The Future is Calling, 8-9 Nov 2018, Glasgow, UK. (Unpublished)

#### **Downloaded from**

https://kar.kent.ac.uk/74104/ The University of Kent's Academic Repository KAR

The version of record is available from

#### This document version

Presentation

**DOI** for this version

#### Licence for this version

**UNSPECIFIED** 

#### **Additional information**

#### Versions of research works

#### **Versions of Record**

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

#### **Author Accepted Manuscripts**

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in Title of Journal, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

#### **Enquiries**

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies).

Juli Crocombe, Damian Milton & Richard Mills

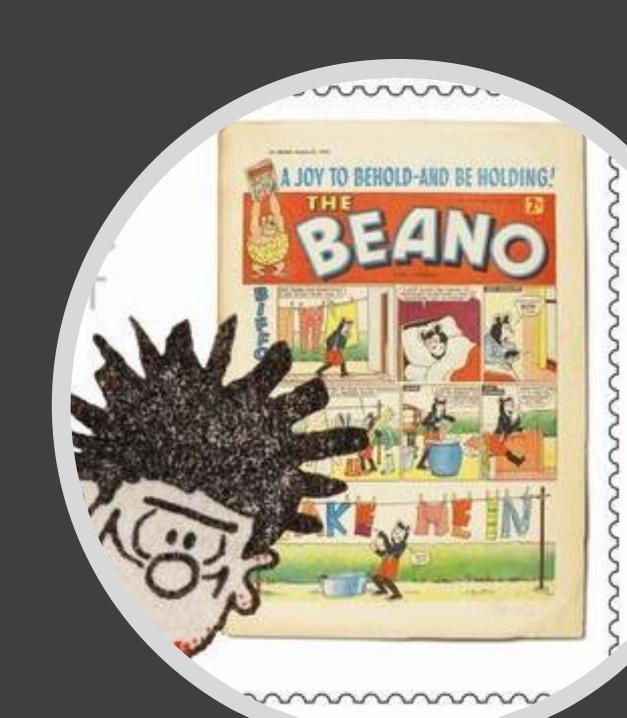
10 rules to ensure autistic people obtain poor mental health support .....and maybe what to do about it



### Rule 1.

#### Misunderstand me

- If you don't understand me call me 'complex'
- If I argue with you diagnose me with a personality disorder
- If I 'shut down' diagnose psychosis
- If I 'melt down' call me 'challenging'



### Rule 1. Misunderstand me

.....and maybe what to do about it

Try to understand me ... please..

- ►listen- to me and people who know me
- >ask me about things I find difficult
- ➤ don't diagnose me with a disorder based on your area of expertise - or just to get me a service
- >don't interpret directness as rudeness
- ►be kind –I need your understanding and help



## Rule 2.

#### Be dismissive

- Ignore the knowledge I might have about myself or my history- you know everything
- Ignore my family or friends. If they persist refuse to speak to them
- Get me to doubt myself make me feel I'm going mad
- Lose your temper with me Be mean



### Rule 2. Be dismissive

.....and maybe what to do about it

#### Respect me

- Treat me with respect- listen to me take your time –get to know me
- Listen to what is 'behind' my words or actions not always the literal meaning —could be stress
- Treat my family with respect- listen to them make the time . We are worth listening to



## Rule 3.

### Don't accept me for who I am

- See my difference, 'way of being or difficulties of engagement as a 'disorder' needing 'treatment'
- Dismiss my history –my interests –my perspective
- Stigmatise me



# Rule 3. Don't accept me for who I am .....and maybe what to do about it

#### Accept me for who I am

- But listen to my difficulties and find ways to help
- Be alert to the possibility of other problems such as anxiety, depression, sensory difficulties or ADHD
- Finds ways to engage me and communicate
- Use respectful and non-stigmatising language





### Rule 4.

### Dispute neurodiversity – and autism

- Do not use accepted diagnostic criteria
- Rely on outdated theory (autism as a form of attachment disorder is a good start). Better still – no such thing as autism
- Ignore any conflicting opinion especially autistic opinion –never discuss
- Under no circumstances undertake training or read anything written by an autistic person

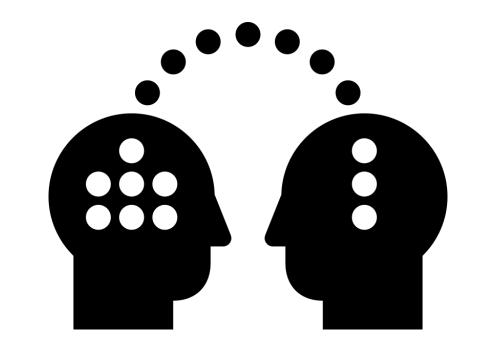


## Rule 4. Dispute neurodiversity & autism

.....and maybe what to do about it

#### Please, please get up to date

- Read widely- undertake training that includes input from autistic people
- Use accepted diagnostic criteria –not guesswork
- Plan <u>with</u> me to address my communication, sensory, social and psychological needs
- Open your mind



### Rule 5.

### Ignore or reframe my stress and distress

 Describe me as having 'challenging behaviour' 'acute psychotic episode'

- Ignore the way others treat me
- Give me antipsychotic medication
- Admit me to a general adult psychiatric ward \ \ preferably noisy and chaotic. Have me assaulted



Rule 5. Ignore or reframe my stress & distress

.....and maybe what to do about it

#### Act on my stress and distress

 Avoid hospital if you can. Do your best to help me at home - or close to home as possible - but make me feel safe

 Ensure that any mental health assessment is done by people with knowledge and experience of autism

• Tell me you are trying to help me. It might not occur to me



### Rule 6.

### **Detain me in hospital**

- Preferably against my will
- See my not 'changing' or 'getting better' or wanting to leave - as grounds for detention. If this makes me anxious medicate me
- Keep me in hospital for as long as possible. This
  will ensure secondary problems -such as losing
  accommodation, relationships and employment



# Rule 6. Detain me in Hospital

.....and maybe what to do about it

#### **Prepare and communicate**

- If I do need hospital prepare me for this. Explain what will happen and when. As much written information as you can
- Be straightforward and direct
- Try to ensure the hospital staff is prepared and aware of my autism in advance
- Involve my family or friends-communicate



# Rule 7.

### Make sure Hospital is stressful

- Lie to me. Do not tell me how long I will be here mislead me
- Give me drugs
- Ensure a chaotic noisy terrifying environment
- Far from home is good- Exclude my family and friends



Rule 7. Make sure Hospital is stressful

.....and maybe what to do about it

#### Reduce my stress

Make Hospital as inclusive (autism-friendly) as possible

 Pay attention to lighting, noise, odours and other potential sources of sensory overload

• Train staff in understanding and responding to autism .

• Use adapted 'talking' therapies

As close to home as possible. Involve my family



# Rule 8.

### Give me drugs

- Experiment with medication when it doesn't work – just add another to the mix
- Describe my continued 'way of being 'as 'resistance' to treatment



# Rule 8. Give me drugs

.....and maybe what to do about it

#### **Know the limitations of drugs**

- Review drug treatment regularly
- Watch for adverse effects. I might not report them
- Ensure long term plans take account of the nature of my autism and my need for stimming, clarity and structure
- Keep to your word regarding plans Please remember I may take things literally. Keep your word





### Rule 9.

Be inflexible, unreasonable & inconsistent.

 Be vague regarding appointments and plansnever put anything in writing

Insist on appointments in noisy or open settings

 Remember - Autism is untreatable so refuse to see me for mental health problems

 See the my relatives as aggressive if they take an interest – If they disagree with you exclude them



Rule 9. Be inflexible unreasonable & inconsistent

.....and maybe what to do about it

### Be flexible, sensitive and tolerant

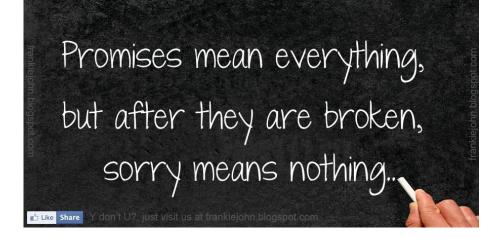
- Make reasonable adjustments even if I appear unreasonable this may be a misunderstanding
- Autism is not 'treatable' but I may have other mental health issues that do need treatment
- Try and see me where and when I prefer
- Work with my family possible some also autistic



# Rule 10.

There is no rule 10.

I promised you one but there isn't one. Get over it.



## Our thanks

To those psychiatrists and mental health professionals who 'get it'

and

All of those autistic people and their families who have inspired us with their stories



# Thank you!

Damian Milton and Richard Mills

www.atautism.org
www.kent.ac.uk/tizard/





AT-Autism