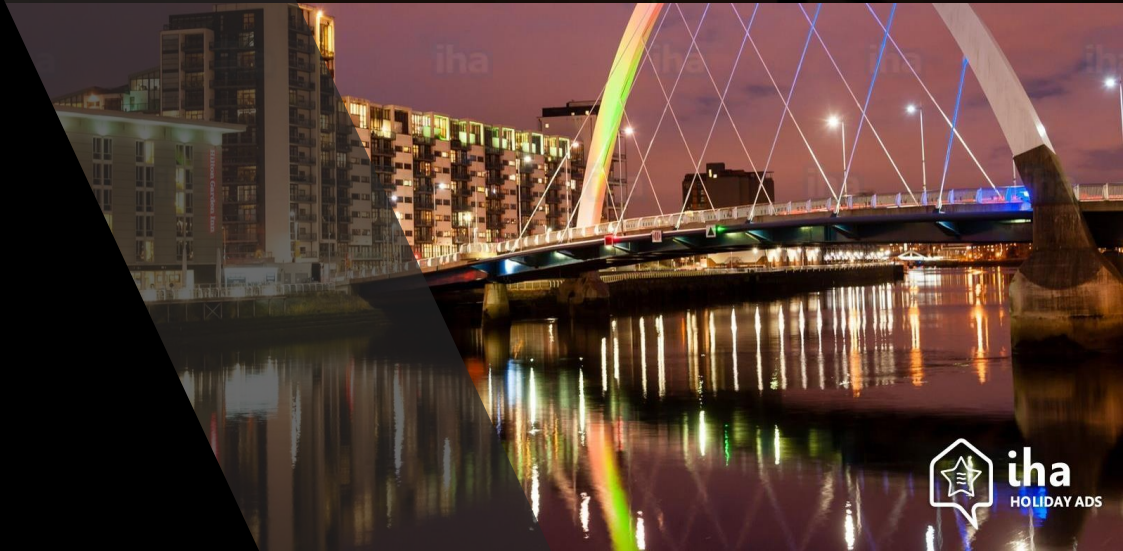


Juli Crocombe, Damian Milton
& Richard Mills

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*



**RESPECT
IS A TWO WAY
STREET**

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- Rely on outdated theory (autism as a form of attachment disorder is a good start).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

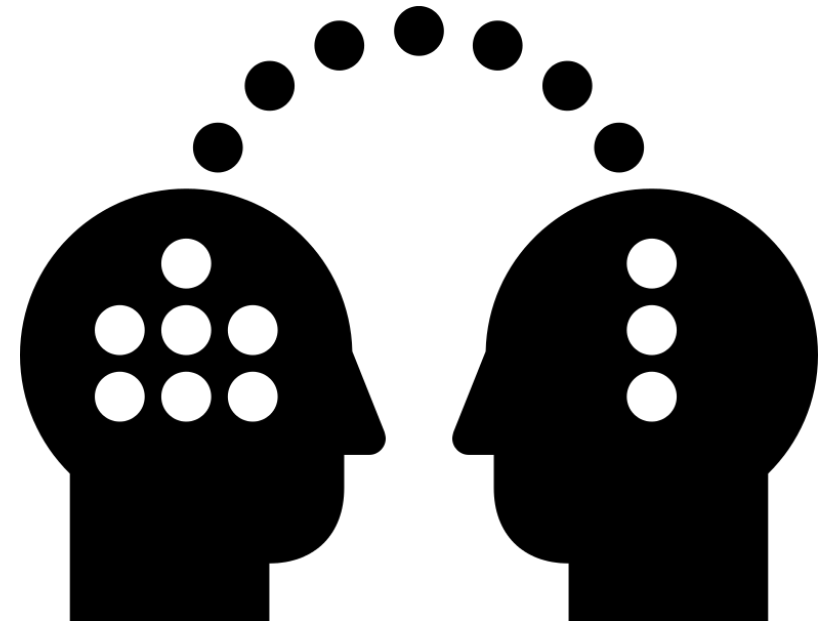


Rule 4. Dispute neurodiversity & autism

.....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 with 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’ or ‘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 plans- never 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

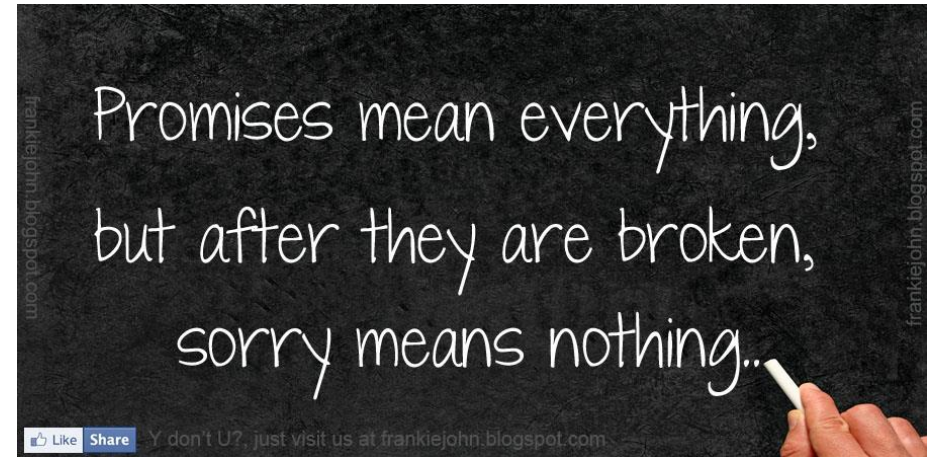
- *Make reasonable adjustments – even if I appear unreasonable – this may be a misunderstanding*
- *Autism is not ‘treatable’ but I may have other mental health issues that do need treatment*
- *Try and see me where and when I prefer*
- *Work with my family – possible some also autistic*



Rule 10.

There is no rule 10.

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

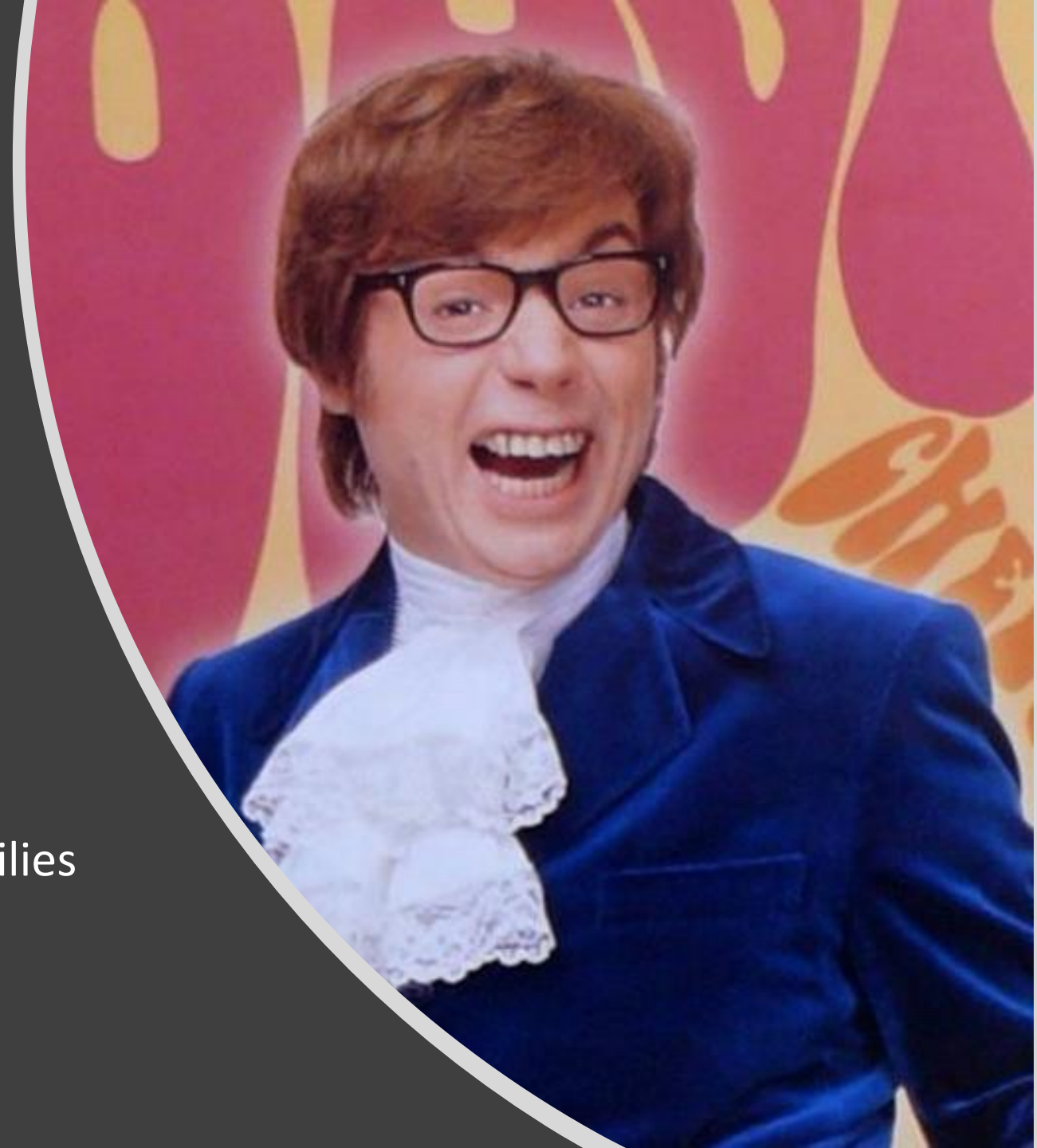


Our thanks

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/



UNIVERSITY OF
BATH

University of
Kent

AT-Autism