Championing Autism – the RCPsych way

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More than 1 in 100 people are thought to have Autism. That means approximately 700,000 people in the UK. Including families, Autism touches the lives of 2.8 million people every day in the UK. (www.autism.org)

Between 48% - 56% of autistic people do not have a learning disability. (www.autism.org)

Autism costs the UK economy £32 billion a year, more than heart disease, stroke and cancer combined. (London School of Economics 2014)


70% of autistic adults say that they are not getting the help they need from social services. 70% of autistic adults also told us that with more support they would feel less isolated. (Bancroft et al (2012). The Way We Are: Autism in 2012. London: The National Autistic Society)

“I’ve always felt like the odd one out, that everyone communicates with information I don’t have” (user feedback)
Objectives

• To quickly recap on Championing Autism Campaign
• To share findings from the first year (from October 2016)
• To encourage debate about models of service
Background

- Autism is term increasingly used (e.g. in the Autism Act 2009 England) to cover all conditions within Autism Spectrum Disorder
- Autism is a neurodiversity not a mental illness
- Different countries within UK and beyond have a variety of strategies and guidance relating to Autism
- All in some way include better training for practitioners and “reasonable adjustments” for Autistic people accessing services
National Strategies

- **England**: Strategy - Think Autism 2014
  - Guidance NICE CG 142 (adults) and CG128 for those up to age 19

- **Northern Ireland**: Strategy - Autism Strategy 2013-2020
  - Guidance - NICE guidance subject to local endorsement

- **Scotland**: The Scottish Strategy for Autism
  - Guidance SIGN CG 145

- **Wales**: Strategy - Autism Spectrum Disorder Strategic Action plan
  - Guidance – NICE guidance
English Statutory Guidance - Think Autism 2014

• Requires NHS and Local Authorities to
• Provide Autism awareness training for all staff
• Must provide specialist autism training for key staff such as GPs and community care assessors
• Can’t refuse a community care assessment for adults based solely on IQ
• Must appoint Autism lead in their area
• Clear pathway to diagnosis and assessment for adults with autism
• Need to commission services based upon adequate community data
RCPsych Championing Autism

- RCPsych agreed a pump priming 6 month project with DH to enhance RCPsych response to Think Autism
- Appointed an Autism Champion. This met a recommendation from Westminster Commission on Autism
- Agreed with DH aims for the project of which pump priming was a preparatory phase
- July 2017 Council approved 3 year extension of Championing Autism for all ages, all abilities, across all faculties and divisions
Project Aims

1. Auditing the autism continuing professional development (CPD) needs of all psychiatrists in practice;
2. Updating and scaling up its existing CPD autism training programme to meet identified CPD needs;
3. Developing and implementing models of best practice in support and selective referral to local specialist autism teams and
Anticipated Outcomes

- Timely ASD diagnosis and appropriate services to refer to;
- Autism friendly mental health services;
- Reduced stress and anxiety – not only for those with ASD, but also, families, carers, social workers, GPs and psychiatrists, who will be better placed to do a good job;
- Improved health outcomes with equitable access to the NHS;
- Reduction in wasted resources by implementing earlier recognition and reducing crisis management.
Work to date

• As Autism Champion I have met with many groups and individuals to listen and learn and raised profile of Autism and Psychiatrists internally and externally as well as participated in multiple events
• Tom, Peter and Terry had funding to update College training material- completed
• Tom, Peter and Terry developing additional elearning for the College and ensuring it complements elearning packages from others
• Ashok has linked with HEE regarding their work in enhancing Autism training offers
• Tom got College agreement to create Neurodevelopmental SIG
Proper Diagnostic Assessment

― Knowing yourself is the beginning of all wisdom ―

Aristotle
Diagnostic Criteria

• Diagnosis is a clinical diagnosis
• Three main domains in ICD10
  • Social Interaction
  • Communication
  • Rigidity/focal repetitive interests
• DSM V now has 2 domains
• Autistic traits common in general population so it is number and significance of traits critical to diagnosis
Diagnostic Tools

• Current diagnostic tools such as Disco, ADOS, ADI all have weaknesses and all have proponents but none are “Gold Standard”

• None replace need for a proper clinical assessment with developmental history

• Tools such as AQ10 and AQ50 have some value in screening for those more likely to need a full assessment but are not diagnostic tools
Ideal Service

• There is no current blueprint for this
• Ideally all would be identified in childhood
• All would have a strengths, needs and aspirations approach to assessment and ongoing interventions
• Main issues needing treating likely to be co-morbidities rather than Autism but will need to identify what reasonable adjustments are for each person at various life stages. It is therefore vital that diagnostic assessment is not simply an Autism Yes/No report
Right to Diagnostic assessment – one time and it is gone

- An Autism diagnostic assessment is once in a lifetime opportunity
- Individuals/families as well as health and social care services, education and employers need to know which traits and how they impact – positive and negative
- Co-morbidities common – what are they and what are the interactions?
- Individual formulation key- diagnosis plus “so what”
If an adult can access an assessment for an autism diagnosis they can identify their own strengths, needs and aspirations enabling them to build on their strengths and skills and access reasonable adjustments to optimise their functioning.
Know the person

- Informant history vital for establishing baseline
- Episodic relapsing remitting presentation - need to ask what needs correcting
- Level of need may have been hidden until long term carer no longer able to do so - may need habilitation
What is current position

- In England each CCG has statutory duty to commission an Adult Autism diagnostic pathway
- No national definition of what it should contain or who can do it or numbers to be seen
- SAF- a Local Authority self report not reliable regarding NHS activity
- MHMDS from April 2018 will start to capture data on diagnosis by CCG
- Psychiatrists with adequate time, training and resources can be key part of this commissioned and funded adult Autism diagnostic pathway and are in some but not all services
So why not do as part of CMHT

- Usually put forward by people who don’t work in adult CMHTs
- They don’t have time or resources to do it
- Increasingly have to have a here and now focus
- Struggling to cope with current demands
- Their prime need is to know how to best respond to people already diagnosed as Autistic who are increasing in number
Reasonable Adjustments

• Autism isn't an exclusion-access depends on level of co-morbidity and barriers based on autism should not make this harder.
• A truly co-produced care plan will be driven by the person’s aspirations
• If an intervention doesn’t interest an autistic person it is likely they won’t invest in it
Prevalence

• There is debate as to whether prevalence increasing or better case finding. Probability mainly if not entirely the latter
• Previous work missed many boys/men and girls/women who did not fit with an expected picture of boys with Learning Disability.
• Is a neurodevelopmental disorder so must be evidence traits present from relevant developmental stages
WHY
DOES IT
MATTER
Autism in adults is still poorly understood

- Prevalence rates are estimated in the range 0.8-1.5% of population reflecting current lack of knowledge
- Most Autistic people alive today weren’t diagnosed at school
- The diagnostic assessment is the only statutory requirement. There are very few examples of CCGs commissioning specialist post diagnostic services other than for complex tertiary inpatient care. Most Autistic people will therefore be accessing mainstream services for physical and mental health care needs
The Result is…..

- Little is known about the course of Autism in adults and what promotes success
- Research evidence increasingly suggests that it is comorbidities and the impact of negative life experience that create the major health issues
- The research data suggest high rates of mental and physical disorders and up to 20 years premature mortality.
Awareness of diagnostic overshadowing
Early death and physical health

• The largest ever autism mortality study (ASD n = 27,122; OR:2.56)

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Total n ASD</th>
<th>Risk ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mouridsen</td>
<td>Denmark</td>
<td>341</td>
<td>1.9 (1.3-2.8)</td>
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<tr>
<td>Pickett</td>
<td>USA</td>
<td>13111</td>
<td>2.5</td>
</tr>
<tr>
<td>Gillberg</td>
<td>Sweden</td>
<td>120</td>
<td>5.6 (2.5-10.5)</td>
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<tr>
<td>Bilder</td>
<td>USA</td>
<td>305</td>
<td>9.9 (5.7-17.2)</td>
</tr>
<tr>
<td>Schendel</td>
<td>Denmark</td>
<td>20,492</td>
<td>2.0 (1.4-3.0)</td>
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### Early death and physical health

#### Causes

<table>
<thead>
<tr>
<th>Causes</th>
<th>Odds Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suicide</td>
<td>7.55 (6.04-9.44)</td>
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<tr>
<td>Neurological</td>
<td>7.49 (5.78-9.72)</td>
</tr>
<tr>
<td>Circulatory</td>
<td>1.49 (1.27-1.75)</td>
</tr>
<tr>
<td>Congenital</td>
<td>19.10 (11.94-30.55)</td>
</tr>
<tr>
<td>Digestive</td>
<td>3.31 (2.25-4.87)</td>
</tr>
<tr>
<td>Endocrine</td>
<td>3.70 (2.34-587)</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>1.80 (1.46-2.23)</td>
</tr>
<tr>
<td>Respiratory</td>
<td>2.68 (1.99-3.62)</td>
</tr>
</tbody>
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_Hirvikoski et al., 2015_

<table>
<thead>
<tr>
<th>Illnesses</th>
<th>Odds Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular disease</td>
<td>2.54 (2.13-3.02)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2.18 (1.62-2.93)</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>32.73 (7.76-137.96)</td>
</tr>
<tr>
<td>Stroke</td>
<td>2.12 (1.03-4.37)</td>
</tr>
</tbody>
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_Croen et al., 2015_
We need to mitigate risks

- Much of this additional morbidity and premature mortality is avoidable or treatable.
- Autistic people can struggle with communication and social interaction so problems often missed or misunderstood.
- Autistic people experience very high rates of social exclusion including bullying and often develop mood and anxiety problems and increased rates of suicide.
Reasonable Adjustments

• It helps them and key others to see their strengths and reduces mood and related issues
• It makes it easier to identify and deliver reasonable adjustments
• Reasonable adjustments can enable Autistic people to have much more successful lives
• Many will have contact with multiple physical and mental health and social care services due comorbidities
• Health and social care staff knowing how to respond appropriately to Autistic people including reasonable adjustments can help make significant differences
Autists are the ultimate square pegs, and the problem with pounding a square peg into a round hole is not that the hammering is hard work. It’s that you’re destroying the peg.

Paul Collins, Reproduced by Patient Talk.org
Aim is to help person be successful Autistic person not fake it as a Neurotypical
Experience and training needs survey

- Little is known about psychiatrists’ views and experiences of working with Autistic people.

This 15-20 minute survey seeks to do just that. The information you provide will critically identify what works and what doesn’t work for you, as a psychiatrist, and for the individuals and families you support. It will also inform the design of training materials as part of the RCPsych’s strategy for autism.

- We very much hope you would like to take part! You can access the survey here: https://www.surveymonkey.co.uk/r/KQZ7QVH
Thank you

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