



Autism Conference 2022

Promoting Personal Growth Through
Autism Intelligent Practice.

#OrbisAutismConference22



Suzanne Lawrence

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Orbis Education & Care





Pamela Hirsch





Coffee Break



Sensory Trauma

Proactive Regulation, Co-regulation, and Thriving



What to expect...

About Us



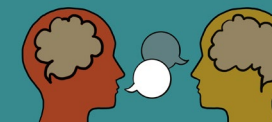
Background to our work



Presentation about Sensory Trauma and Sensory Regulation



Question and Answer session



Even in the same room at the same time, autistic people frequently tell and show the world that our sensory experiences may differ from the sensory experiences of other people.



You may hear this door slam and it might make you jump slightly and look up. Your brain and sensory processing system have perceived it as a slight annoyance, nothing more.

Your response is proportional to your experience, and you carry on as you were.



I may experience the same door slam as a sudden, severe auditory pain – and just like you my brain and body respond in a proportional way. But this time it is to a perceived threat.

I might cower, fall to the floor in a foetal position or lash out at you if you're too close.

We've both responded authentically and genuinely to our experience – our responses differ because our neurologies and experiences differ. My reaction is not an over-reaction or over-sensitivity – you probably respond in a similar way to me when you perceive threats too.



The events experienced by autistic people as physically or emotionally harmful or life threatening may not necessarily be the extreme events typically associated with trauma.

Sensory Trauma may arise from ordinary, everyday activities such as taking a shower, greeting your family, or having breakfast.

#SensoryTrauma

www.autismwellbeing.org.uk



We live in unpredictable and everchanging environments.

The potential for Sensory Trauma may be there all the time for autistic people.

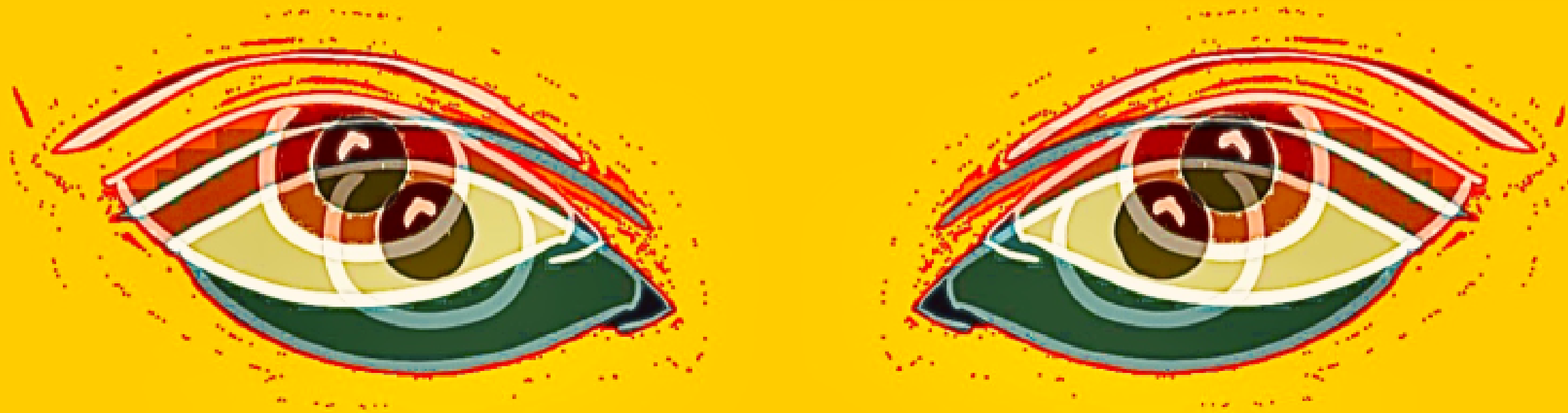
This may mean an autistic person is hypervigilant and alert and finds the world a very unsafe place.

Being physiologically activated in this way can have long lasting effects.



#SensoryTrauma

www.autismwellbeing.org.uk



Autistic people often spend their time in busy environments and the company of other people. This provides frequent opportunities for potential Sensory Trauma. This could be whilst moving around a busy school, working under fluorescent lighting in an office, or coping with the smell of traffic fumes and people in town.

#SensoryTrauma

www.autismwellbeing.org.uk

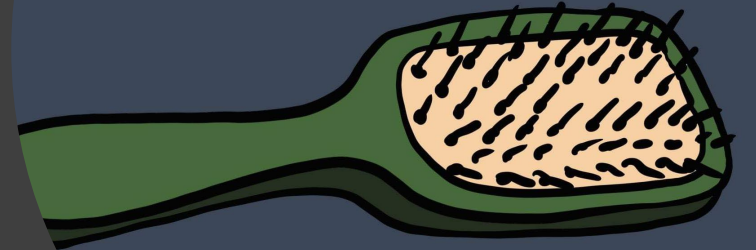


The frequency and ordinariness of events that may cause Sensory Trauma are around us all the time.

For autistic people, the expectation, anticipation, experience, and effects of Sensory Trauma may form an unavoidable part of day-to-day life.

#SensoryTrauma

www.autismwellbeing.org.uk





An event causing Sensory Trauma to an autistic person may be perceived as inconsequential by non-autistic people in the same environment – if perceived by them at all.

The autistic person's reaction may be viewed as “challenging behaviour”, overemotional, or maybe not even accepted or believed – simply because the event may not be recognised as traumatic to other people.

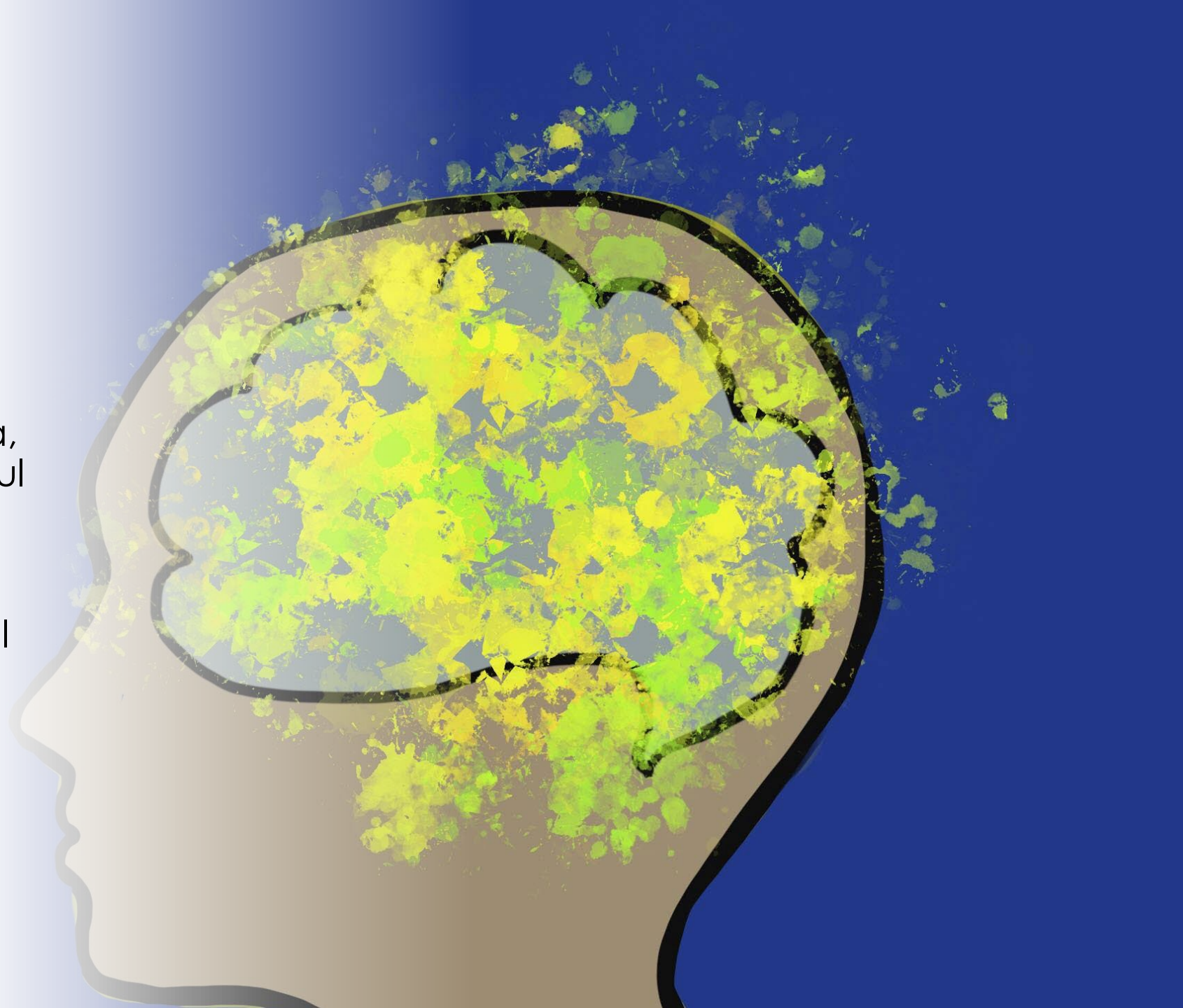
#SensoryTrauma

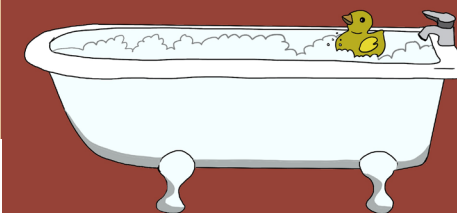
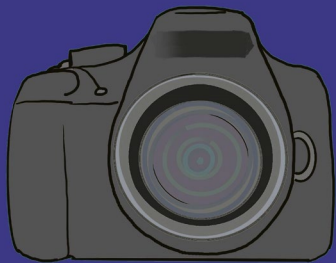
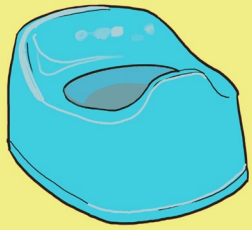
www.autismwellbeing.org.uk



When an autistic person experiences Sensory Trauma, their reaction to these painful or distressing experiences is not due to an inability to cope or an over-reaction – their response is proportional to their experience.

#SensoryTrauma

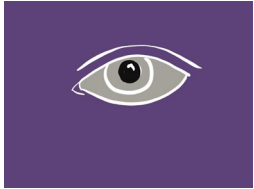




For autistic infants as for autistic adults, sensory trauma may be afforded by the ordinary events of everyday life – eye contact, eating food, wearing clothes or being kissed or hugged. *Sensory Trauma: autism, sensory difference and the daily experience of fear (Fulton et al., 2020)*



Auditory



Visual



Olfactory



Tactile



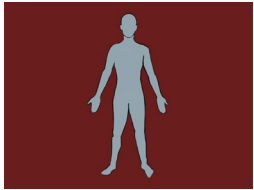
Gustatory



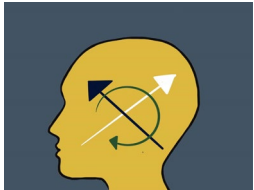
Interoception



Proprioception



Vestibular



autism
wellbeing

Sensory Regulation



We need to be in a calm and alert state to be at our best for learning, growing and getting the most out of life – just like this wise owl in the drawing. Emotional and sensory regulation is about getting the balance just right.



If we are too busy like this bee, we need to down-regulate.

If we are lethargic like this sloth, we will need to up-regulate

Proactive Regulation



Many Autistic people tell us they are dysregulated by Sensory Trauma on a daily basis. Being dysregulated makes it difficult to interact with other people, learn, work and thrive. The world can feel unsafe to Autistic people, and this can lead to hypervigilance. This makes sensory regulation and coregulation even more difficult to achieve.



Proactive Regulation is a term we use at Autism Wellbeing to describe ways we can become regulated and remain regulated when going about our daily lives.

Proactive Regulation



Proactive Regulation can feel difficult to achieve because the world is unpredictable and potentially overwhelming.

Autistic people have many strengths that are unique to each individual – these could include determination, focus, and performing well when routines and structure are in place.



Playing to our strengths is part of Proactive Regulation.

Some people plan into their days hobbies, self-care, and sensory based activities such as music, dancing, sports, and enjoying smells and tastes.

Proactive Regulation



Proactive Regulation includes doing activities that are regulating BEFORE we place ourselves in situations where we may become dysregulated. It also includes having equipment, ideas, or strategies in mind to use when we need them.

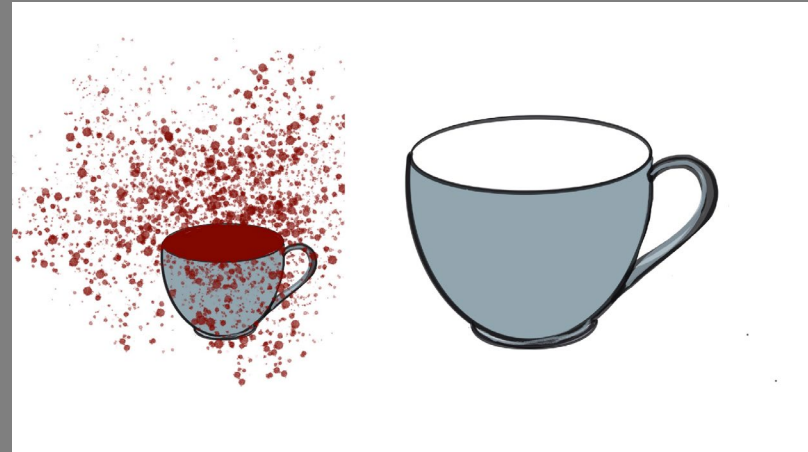


Sometimes that means recognising that certain activities are likely to be distressing or traumatising – and therefore avoiding or delaying these activities, finding an alternative, or asking for help.

Proactive Regulation



Proactive Regulation is something everyone can do.
Autistic people may find it particularly useful because often the world has too much or too little sensory input for us to process.



When an autistic person experiences Sensory Trauma, our reaction to these painful or distressing experiences is not due to an inability to cope or an over-reaction – our response is proportional to what we have experienced via our sense systems.

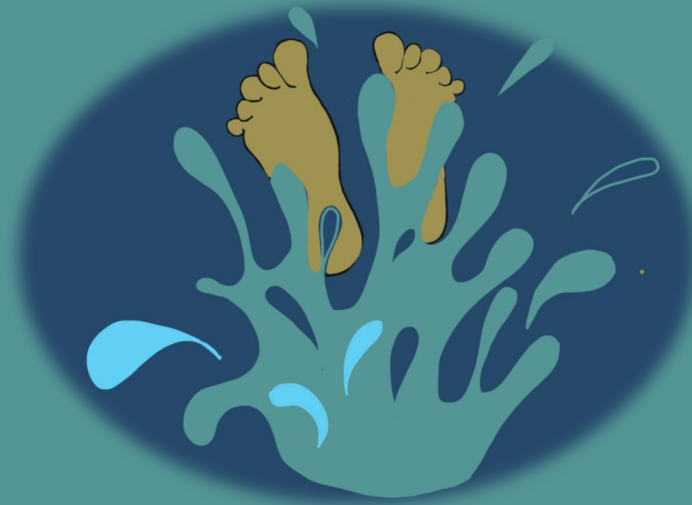
Sensory Trauma: Autism, sensory difference and the daily experience of fear (Fulton et al. Autism Wellbeing Press 2020)

Proactive Regulation



Proactive Regulation includes using regulating activities and actions throughout the day.

Learning about our sensory profile – those sensations we like and dislike – and avoid or seek out, will help identify which activities are most regulating.



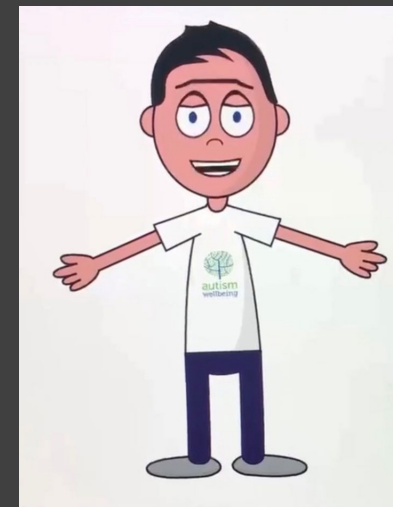
Which of these ideas appeal to you?

Jumping. Stimming. Listening to music. Sipping an ice cold drink. Categorising your CD collection. Inhaling the delicious aroma of your morning coffee. Cuddling a pet. Sniffing a favourite soft toy. Fiddling with a sweet wrapper.

Emma



Rorie



SENSORY TRAUMA

Autism, sensory difference and the daily experience of fear .



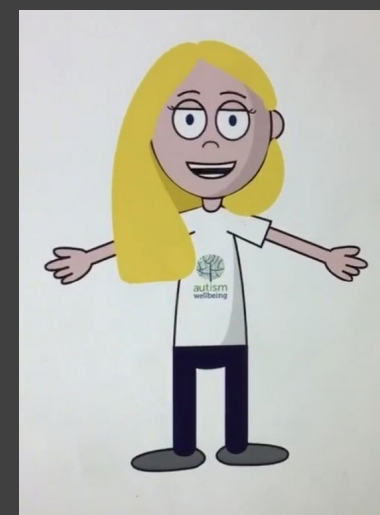
Dr Rorie Fulton / Emma Beardon / Kate Richardson / Dr Rachel Jones



www.autismwellbeing.org.uk
www.facebook.com/AutWellbeing



Kate



Rachel



Lunch Break



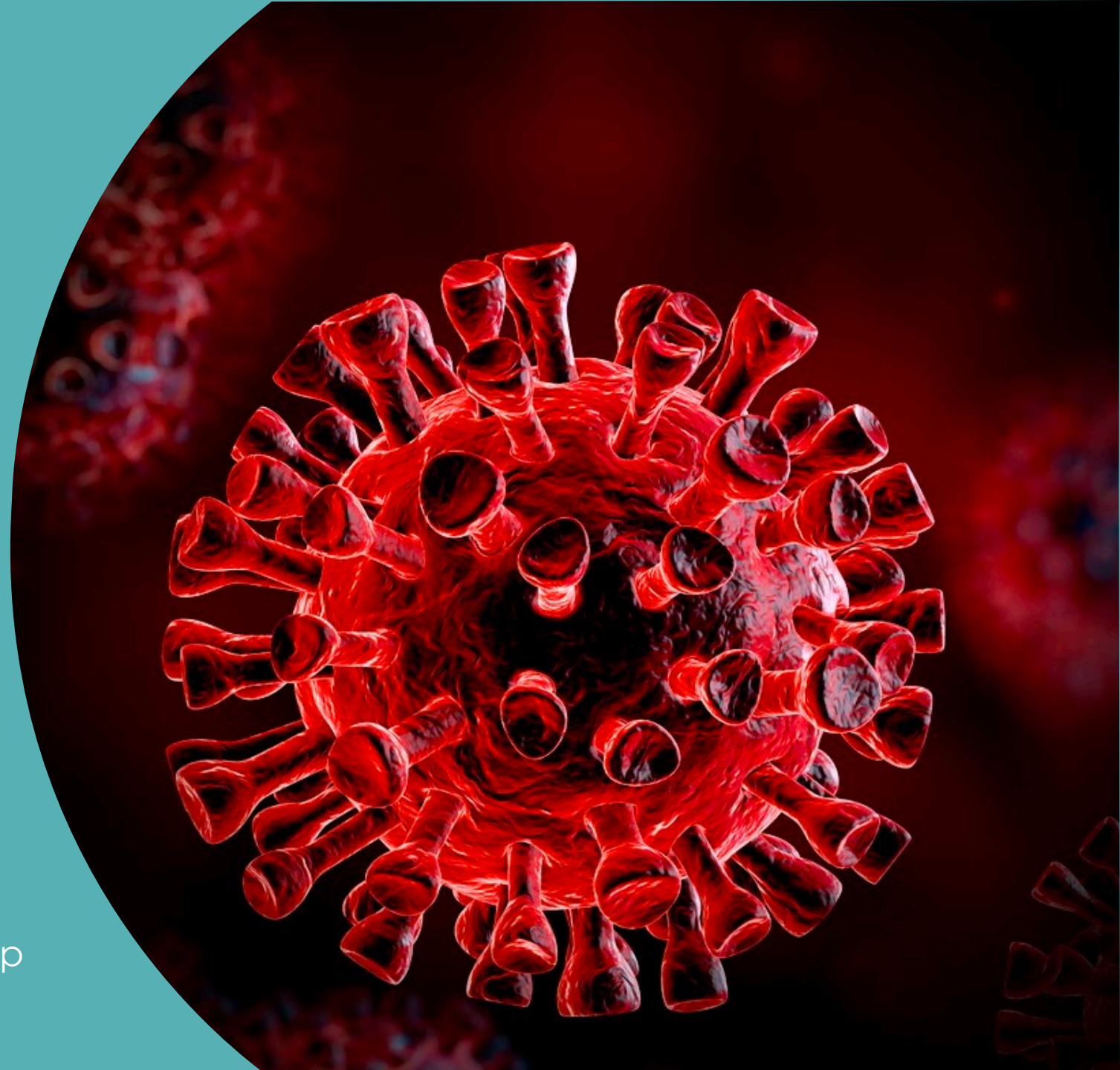


Has Covid made services intelligent?

Dr Peter Carpenter

Hon Lecturer, University of Bristol

Chair Royal College of Psychiatrists
Neurodevelopmental Special Interest Group



Has Covid Made Services Intelligent?



Plan

- The way we were
- COVID
- Where do we go?
 - process
 - how do we set diagnostic standards

Has Covid Made Services Intelligent?



Warnings

I am English!

Retired so not currently licenced

Mainly Adult

Still involved in developing autism professional networks

Chair of College Neurodevelopmental Psychiatry group.

Helped develop the SCAN clinical interview for autism & the College Psychiatrist's interview guide



So where were we?

How far back?

Wales Regional Partnership Boards

Autism partnership boards in England

(little funded – little action)

Wales Integrated autism services, 2016

Wales, Code of Practice, 2021

Wales - Adult Diagnosis - Care Programme.

Autism seen as specialist

NICE Clinical Guidelines 128 & 142

England based on Specialist teams

Scotland – mainly by CMHT

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Assessment

Almost always face to face

Some telephone interviews

'gold standard interviews'

ADI-R

DISCO

- abbreviated

ADOS-2

AAA

Research design rather than clinical

Commercial copyright prevents easy update

Based on older concepts of autism

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Always told could not do online

Where is the policy – we have to have policy on it.

security

making and keeping video files

fear of risk

Interviews can occur on phone - but usually relatives

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Support Systems Clinicians

Royal College Psychiatrists Interview schedule and video clips

South West Community of Practice
Started 2010

Wales Community of Practice
Meet regularly

Training face to face
everyone – time / energy –
mainly in house, short and risk of stereotyping.
Continuing Professional Development – some online

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Covid

England and Wales

Many teams diverted

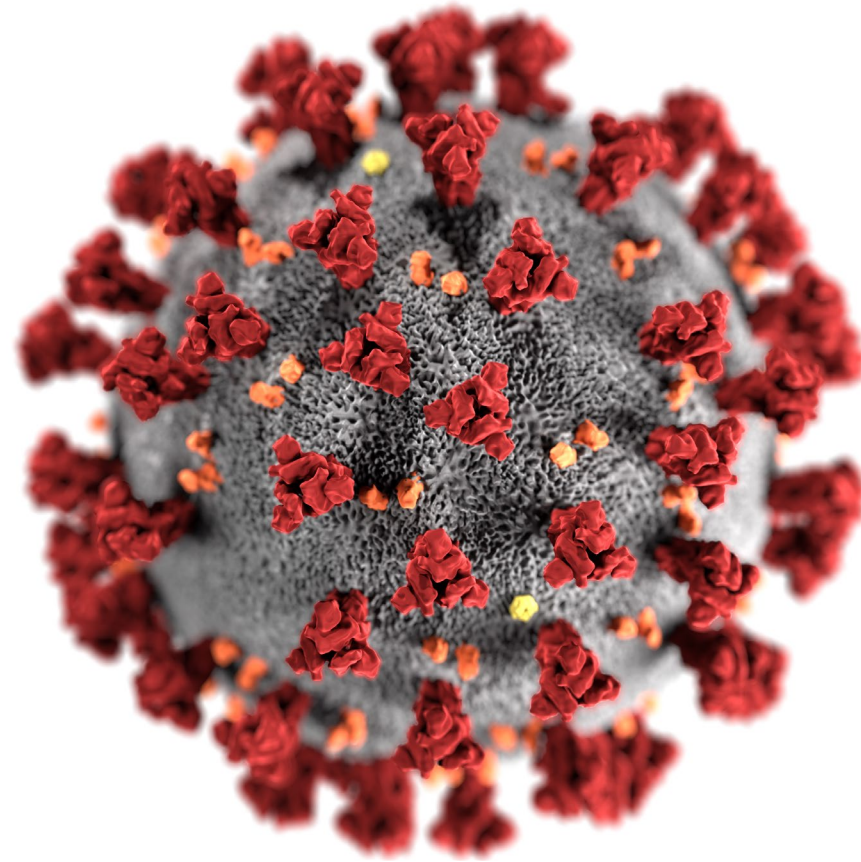
Long WL longer

Ban on F2F

F2F with masks and screens

People

In hospital with COVID





Change in system

Telephone interview - now video as well

ADI-R

Disco

or do your own – a semi structured interview

F2F assessment

Video assessment

ADOS only licenced for F2F

Bosa – Brief observations of Symptoms of Autism

Bristol ideas

Or we give a provisional and see face to face later.

Feedback on tests generally good.

Has Covid Made Services Intelligent?



Support systems for autistic people

Difficult F2F

?Online

When teams diverted in NHS

Has Covid Made Services Intelligent?



New support systems clinicians

Online discussion group for online diagnosis

South West Community of Practice - online

Wales Community of Practice
could be hybrid – now online.

Training online

everyone – at your leisure or at timetabled points

Continuing Professional Development now mainly online

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Challenges

Standards of diagnosis about process

- not content / threshold

- need to develop

- E.g. boundaries with other conditions

ICD11 now here.

- not big change from DSM5



The Brave New World?

NHS and SS in Crisis
manpower

terrifying waiting lists

Most people seen after spent year or more living autism
Rise of complaint in those not diagnosed.

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Brave new world

F2F contact less important

Telephone

Email etc.

Video

New skills

observations not limited by ADOS

It's a clinical diagnosis not an algorithm

Pressure to develop GP skills

All clinicians aware of autism – but to what level.

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Brave New World

Online diagnosis more feasible

Private diagnosis on line for some time

Can do from anywhere – patient or clinician

Rising waiting lists – farm it out

but who monitors outcome

if diagnoser does not have to face follow-up – tempting to say yes to all.

no adverse feedback

We have no quality standards for diagnosis

standards abound but they are for process not clinical decision

Has Covid Made Services Intelligent?



New Standard Letters

Much of time spent on writing the letter - so others do not question
but also letter for GP

Letter for patient to show others.

What is needed?

Decision and tools /clinicians used to make diagnosis

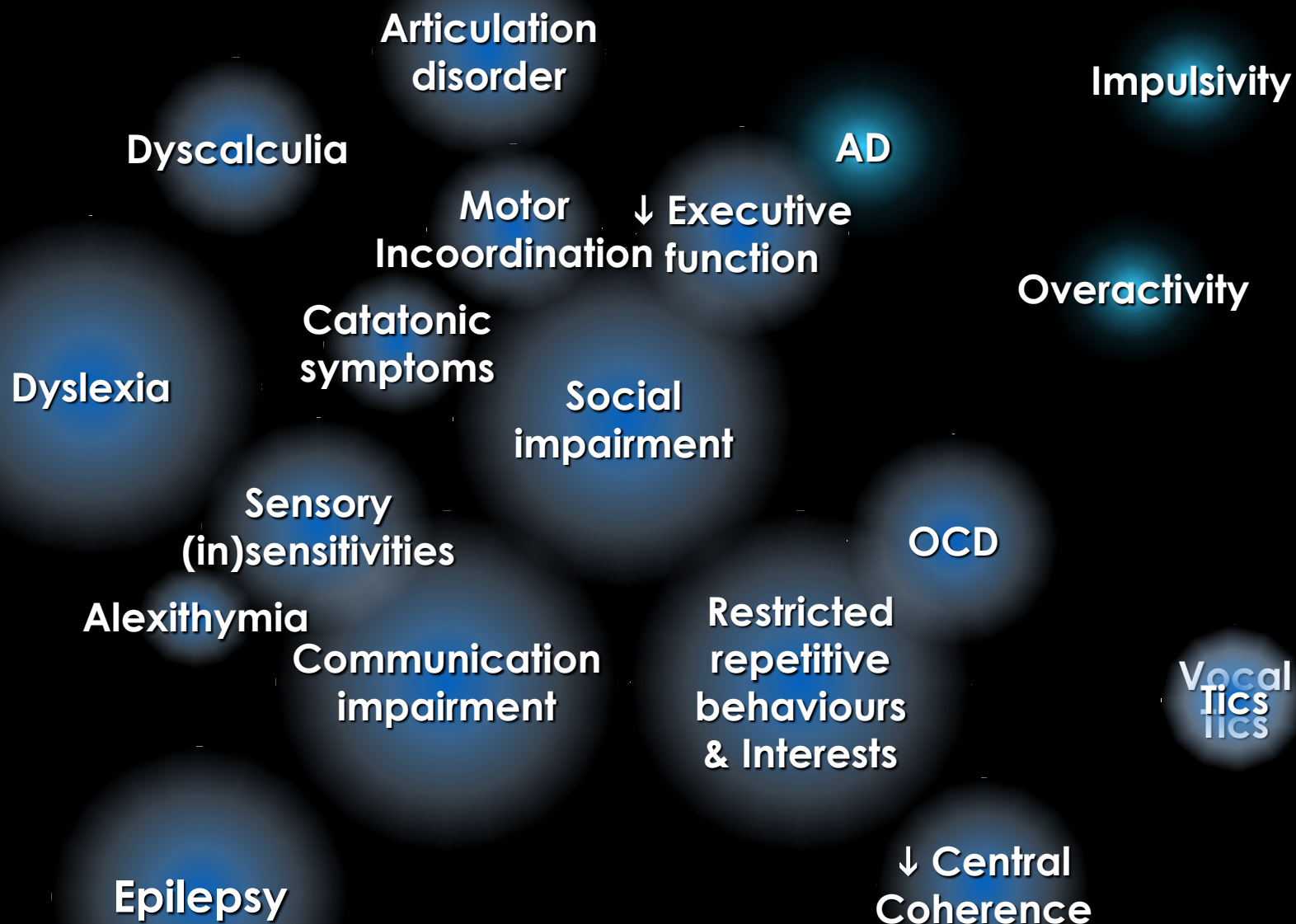
Outcomes and recommendations

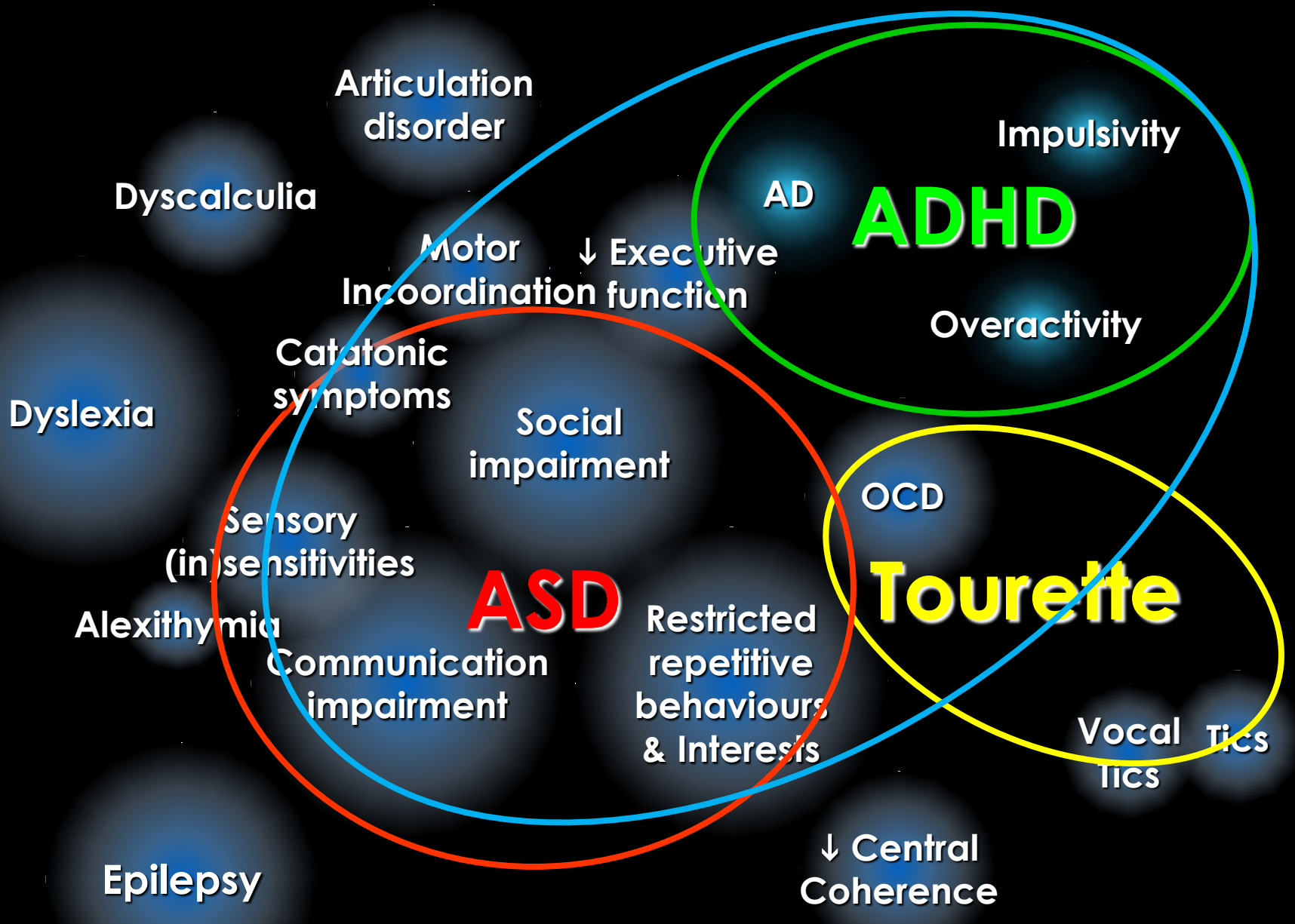
co-authored strengths and passport - ?written by patient

But push for standardised tools / diagnosis by algorithm as cheap/needs fewer skills.

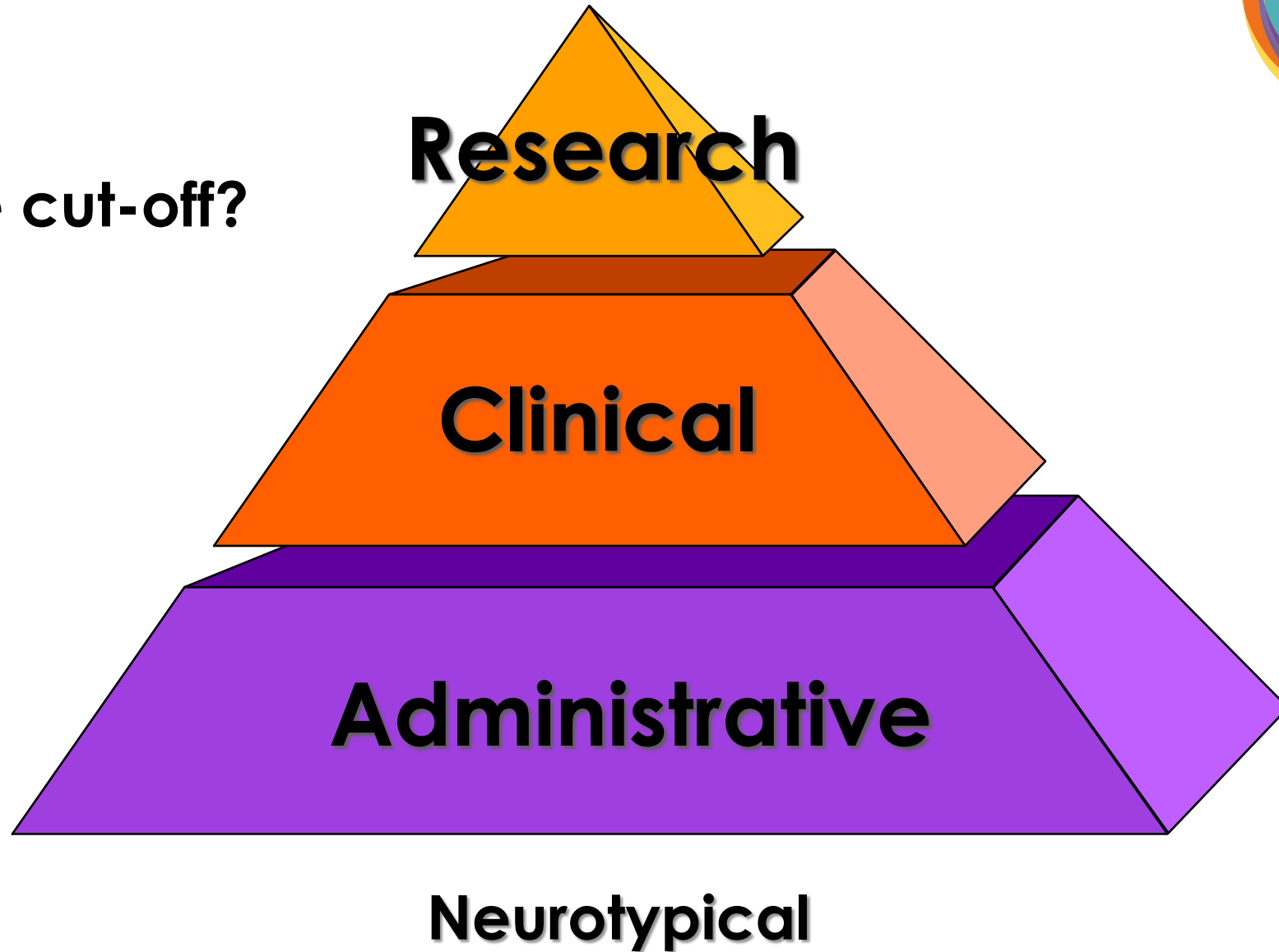


The wide, star-studded sky



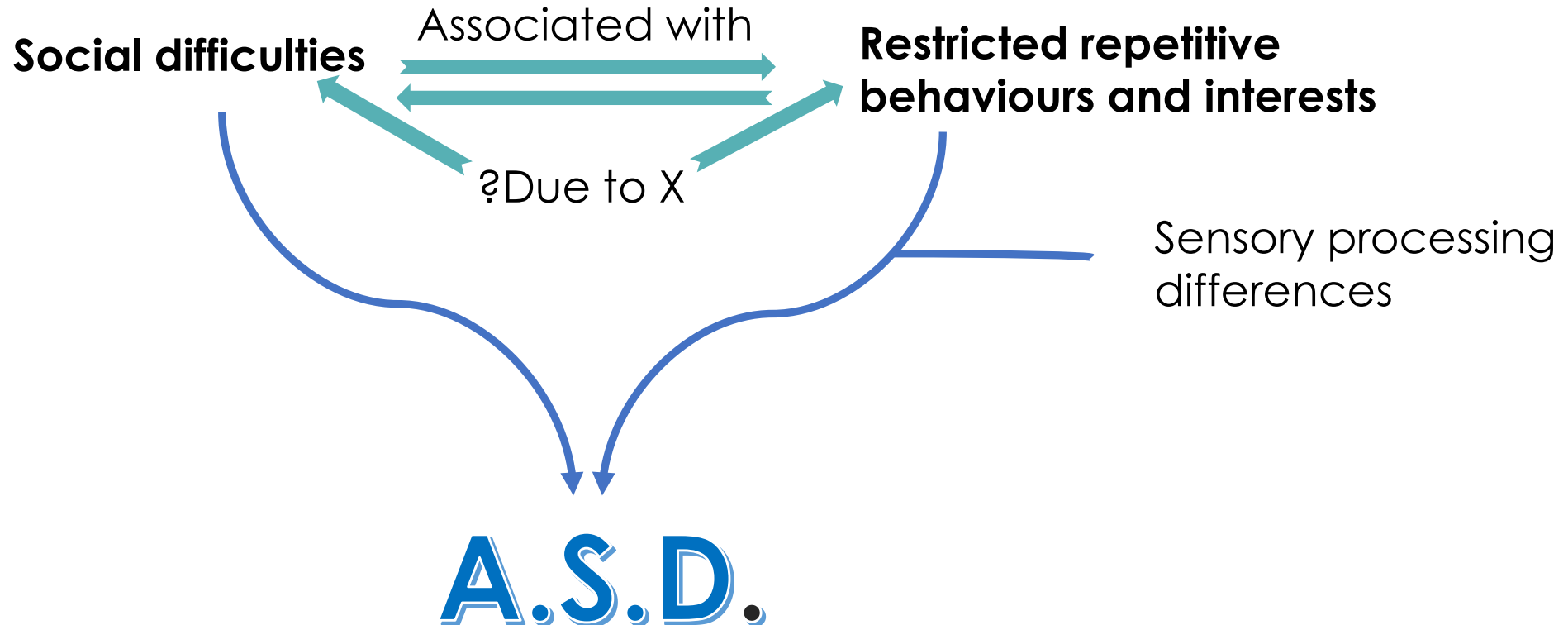


Where to set the cut-off?



Personality disorder
Early chronic PTSD/
Communication disorders
Dyspraxia
Attachment disorders
Etc. etc

Normal at certain periods
development
OCD
Chronic anxiety





Diagnosis

Who sets the standards and clinical boundaries?

Clinicians – deficits and impairments – ICD11 DSM5

People who are diagnosed with Autism? – needs led

Who has the valid ticket?

But how does it change? Redefine the international criteria.



Brave new world

Bigger autism specialist teams **or** more expectation just part of usual team work
so do you only get seen if severe distress / suicide/ psychosis

Link to autism strategy, England?

CoP work in wales

Arguments over diagnostic criteria

Arguments over who sets them

Arguments about how diagnose



Thoughts?



Supporting my Autistic Children

Nada Brothers

April 2022



Introductions



- Who am I
- What is important to me and my identity
- What do I do
- What are my interests
- Why am I here



Uros

Early development

Start of concerns

Diagnosis

Journey

Billy

Early development

Start of concerns

Diagnosis

Journey

Differences for my journey with Billy

Impacts of Diagnosis and Difficulties Getting One, Twice!!



- No knowledge of autism,
- Lack of knowledge of professionals in relation to autism
- Constant battle, over a year, accused of over-protective, paranoid
- Failure of professionals and organisations to listen
- Understanding
- Acceptance
- Difficult to get any help from professionals

Journey From Diagnosis to Age 13, Pre-Residential Care



- Key Points;
- Grief
- Acceptance,
- Judgement from others
- Lack of professional understanding
- Difficulties in meeting both Uros and Billy's needs, conflicts
- My needs, not met
- Small world of three'
- Importance of social workers at this stage



- Closed existence
- Importance of social worker
- Exclusions
- Home or residential

Finding a happy place and the right environment



If I don't let them go, I can't let them grow.....



Uros

- What happened
- Professionals not listening
- Negative health impacts from professionals not listening and getting the support wrong, wrong places initially
- Challenges
- Poor quality of life
- Restrictions

Billy

- What happened
- Failed placements cause damage to both
- Both ended up in Assessment and Treatment Units

“Lowest point of my life, no hope, ripped apart, there is no point to continue, life of my children is going to end”



- Placements found
- Involvement
- Moving in
- Hiccups
- Successes
- Celebrations

Key Staff Skills



- Honesty
- Good relationship
- Easy to talk to need to know the good the bad and the ugly
- Respect parent as individuals, I am different to Mrs Jones
- Value given to staff
- Collaborate and work together
- All have same goal for B and U
- I feel part of the team, my extended family
- Warmth
- Personality and character of Nada



Key Provider Attributes



- Positive attitude
- Listen
- Understand
- Accept
- Respect
- Adapt the Environment



Key Provider Attributes Continued...



- Value individuality
- Nurturing interests
- Importance of right staff, manager
- right Occupational Therapist,
- right Speech and Language Therapist,
- Importance of all working together





- Opportunity to live a life and not be statistic, take risks
- Opportunity to be Billy,
- Opportunity to be Uros,
- Opportunity to grow and develop
- Opportunity for me to be Nada! (and Mama!)

What Next?



- Happy
- Healthy
- Enjoy
- Keep growing
- Cherish personalities
- Be positive
- Celebrate my amazing children





Q&A Session





Thank you for
coming!

