

ID, Autism and Psychosis:

is it a coincidence, confusion or a thing ?"

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SCHN

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Acknowledgements:

1

Professor David Dossetor who has pioneered this field over the last 40 years and taught all of us at The Sydney Children's Hospitals respect for the dignity and worth of these children and the courage of their families

2

The Neurodevelopmental Team Members at Westmead Children's Hospital for all they have taught me, supported me and encouraged me over the last 30 years

3

Professor Philip Graham who first showed me the power of development as a concept and the privilege of neuropsychiatry as a medical specialty

This talk is.....

NOT about treatment but about **describing the problems** without just using the DSM-5 or the ICD-11

NOT about treatment but **understanding how these three problems** – ID, ASD and Psychosis might be related to one another

NOT about treatment but the answer to this questions **affects every treatment** we will be involved in

Three Brain Disorders - Are they connected?

Intellectual disability – difficulty learning, remembering and solving problems

Autistic Spectrum– difficulty relating, communicating and dealing with social situations

Psychosis Spectrum – difficulty making sense, trusting and telling what is real and not real – ‘holding it all together’





Is there a special relationship between learning,
relating and making sense?

This will help us to know if there is a special relationship
between
difficulties between learning, relating and making sense?

Is psychosis more common in those with intellectual disability and autism?

The answer is yes:

Psychosis in Intellectual disability – narrow definition of schizophrenia **3%** where communication is intact but more broadly in schizophrenia spectrum disorders **11%**

Psychosis in Autistic Spectrum Disorders – more than a third at some time – narrowly **7.8%** and lifelong **37%**

Is it a coincidence, a confusion of understanding, or a very important finding that casts light on all three disorders?

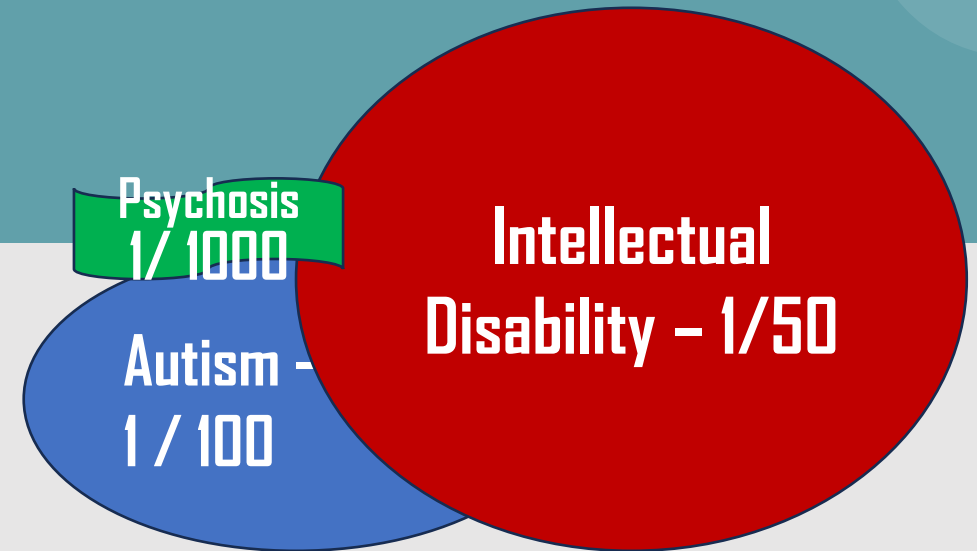
The Relationship – the way many saw it 50 years ago

Intellectual disability was by far the biggest in our minds and overshadowed everything else



The Relationship – the way many saw it 20 years ago

As time passed so the autistic spectrum disorders grew and clinicians started noticing, **particularly in adolescents** and especially at **times of stress**, psychotic symptoms



As treatments grow so does recognition

As recognition grows so do milder, more subtle forms

As more subtle, less severe forms are discerned, people see developmental problems coming earlier

As we see things earlier, we institute treatments earlier and for less severe forms

As we institute treatments earlier, we get better results

As we see better results, we are less frightened and see these young people as part of our society



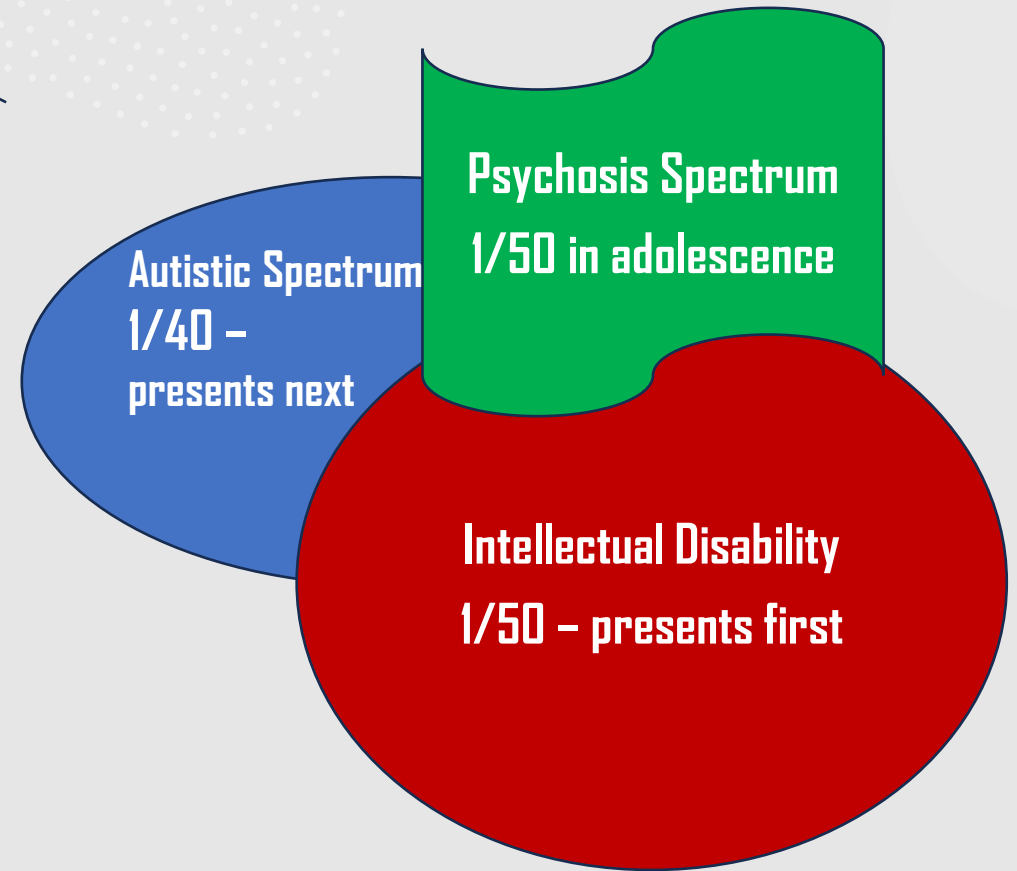
The Relationship as I am seeing it today

Autism and its spectrum has grown and grown in our awareness with early detection and as services become available

Psychosis in all its forms – so called **schizophrenia spectrum disorders** – especially in adolescence, especially with acute stress and chronic trauma – is now as common in youth as intellectual disability

Clinicians are becoming aware that **mild disability is not mild** but invisible, **moderate disability means lifelong care** and severe and **profound disability** require serious, enduring support service, including respite, morphing into **alternate care**

That there is a **neurodevelopmental spectrum of disability** on which these and other conditions fall



Three Brain Disorders

Intellectual disability – difficulty learning, remembering, anticipating and solving problems **1 in 50 children**

Autistic Spectrum Disorder – difficulty relating, communicating and dealing with social situations **1 in 40 children**

Psychosis Spectrum Disorders – difficulty making sense, trusting and telling what is real and not real **1 in 50 children**



Understanding How the Brain Works The Mind

The Mind is **the brain** in action

The Mind is the world outside captured by **the world within**

The Mind is **the self** in experience

*'The Mind is its own place that can make a
heaven of hell and a hell of heaven' Milton*





The Seven (and perhaps 8) R's of the Mind

The Receptive Mind

The Representational Mind

The Risk and Reward Mind

The Reconstructive Mind

The Retentive Mind

The Responsive Mind

The Recursive Mind

The Receptive Mind – from sensory fragments to sensory binding

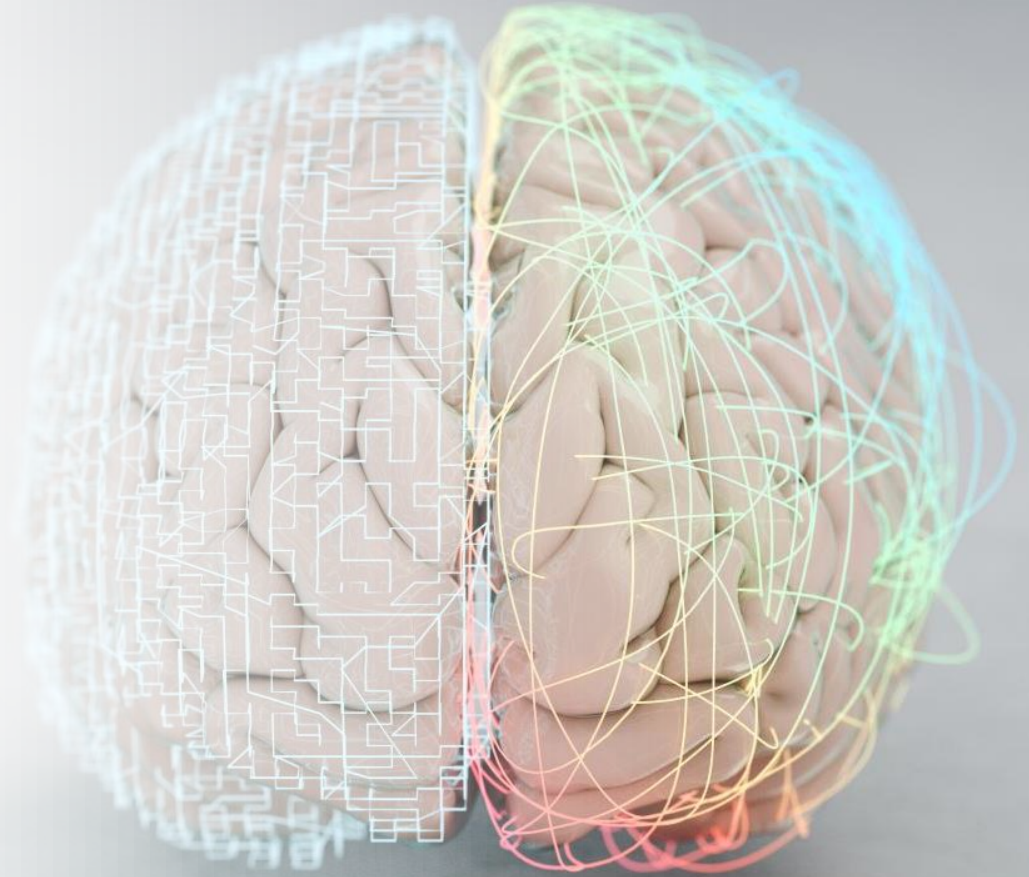
The brain receives the outside world via the sensory system

Sight, sound, smell, touch and taste

These are received separately and grouped into meaningful chunks of experience and

THEN

Our sensory world is bundled together – **sensory binding** so that the outside world of the senses is bound together



What happens when the fragments don't bind together or fall apart?

For some people some of the fragments are missing or the fragments don't fit together easily – intellectual disability

Some fragments are experienced much more or less than others – autistic spectrum disorders – senses and things more than intentions and people

The fragile piecing together of fragments falls apart falls apart, or fits together in ways that should not go together – psychosis – threat is increased and coherence is lost

The Representational Mind

This receptive world – the world received from outside - is pieced together into a coherent picture

UNTIL

The Outside world is a world within ourselves – the inner verse – represented sometimes accurately and sometimes not so much

The outside world and the inside world are kept separate but also integrated so we know within our minds. ME and NOT ME





What happens when the outside world and the inside world are no longer clear?

When we cannot find out, or learn about, or remember the outside world clearly and accurately – intellectual disability

When we cannot accurately work out what people outside are communicating and we don't know how to communicate with them – autistic spectrum disorders

When we cannot distinguish what is inside and what is outside or connect them up meaningfully – psychosis

The world within and the world outside are confused, muddled with one another and at the same time disconnected

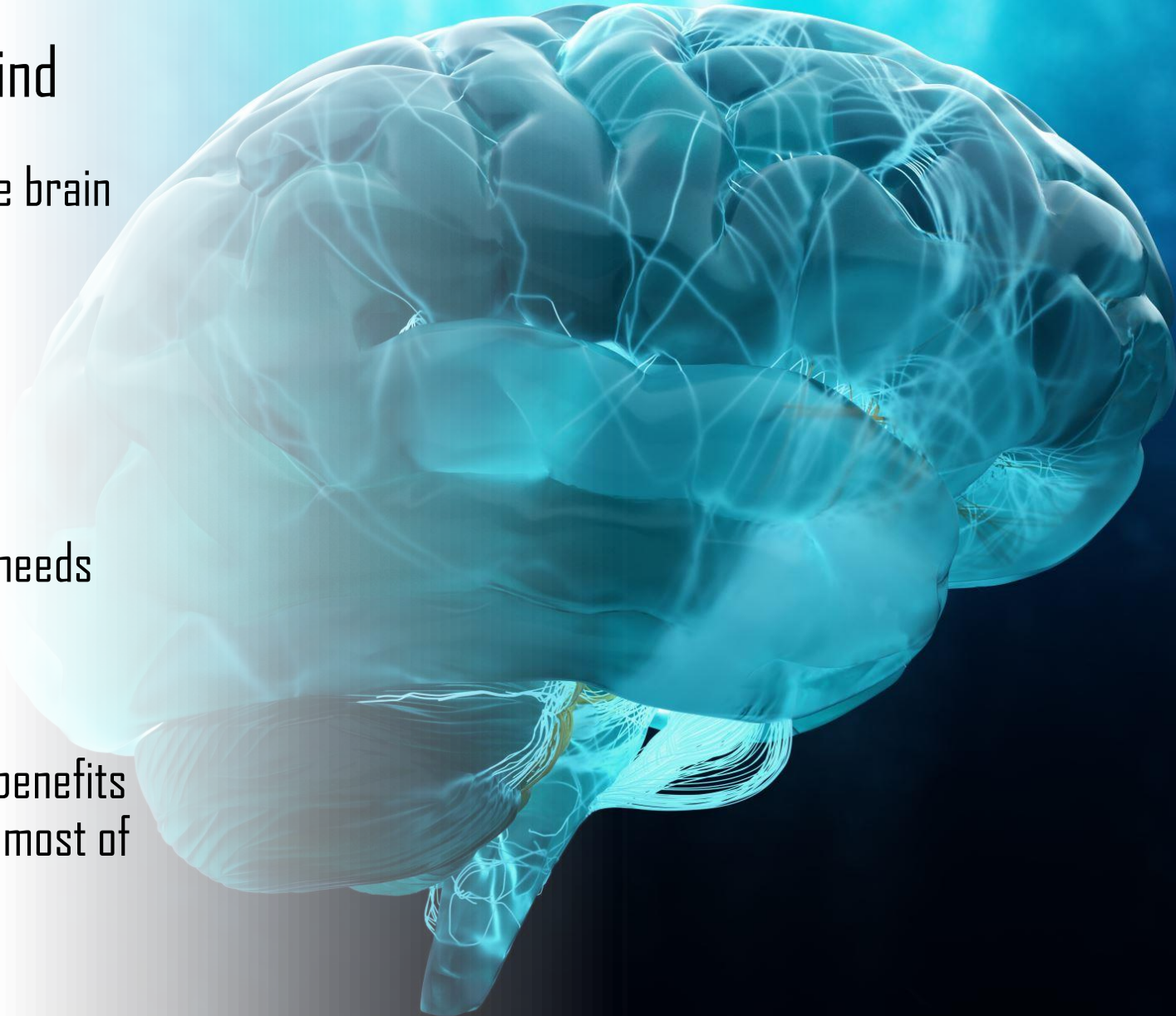
The Risk and Reward Mind

Everything that comes into the brain is scanned for:

Risk of fear and danger
and

Reward – the possibility our needs and desires might be fulfilled

We balance the risks and the benefits without even thinking about it most of the time





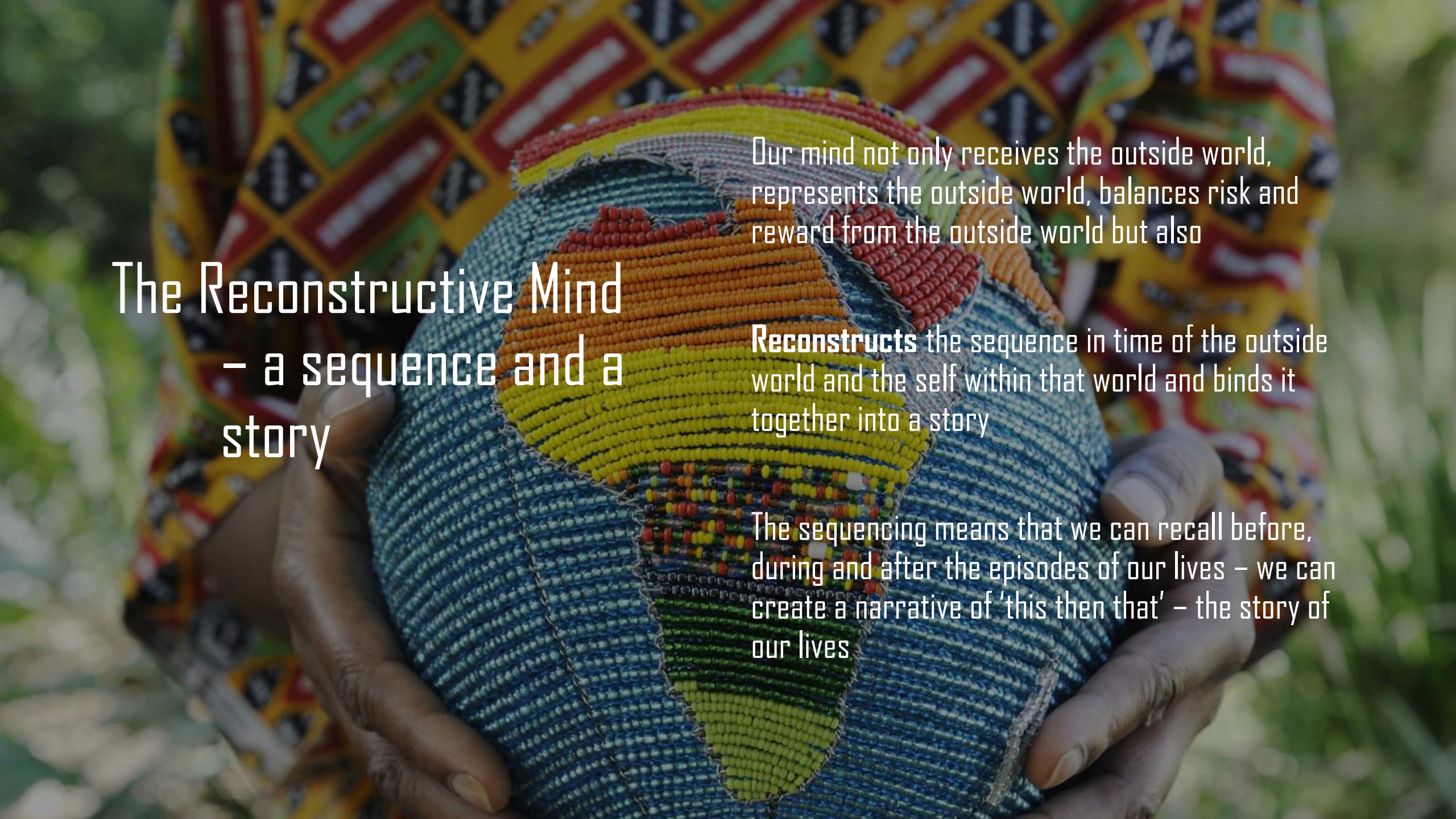
What if we lose the balance?

We get mixed up between what we want **NOW** and what we need to be safe and well **LATER** – we don't see danger coming – intellectual disability

We become relentlessly obsessed with reward and miss the risks – especially the social risks -and for that matter almost everything else – autistic spectrum disorder

We are dominated by fear of what we should not be afraid of and not afraid of things we should be – psychosis

We have become muddled about risk and reward



The Reconstructive Mind – a sequence and a story

Our mind not only receives the outside world, represents the outside world, balances risk and reward from the outside world but also

Reconstructs the sequence in time of the outside world and the self within that world and binds it together into a story

The sequencing means that we can recall before, during and after the episodes of our lives – we can create a narrative of 'this then that' – the story of our lives




What happens when
the sequence gets
muddled?

When the sequence can't be put together – intellectual disability – we don't have clear story

The sequence becomes an endless loop or cycle – autistic spectrum disorder – we need a social story to break the endless loop

The sequence becomes mixed up, bits go missing and other bits fill the gaps – psychosis – we need to remind, retell and reassure about a less frightening, more helpful story

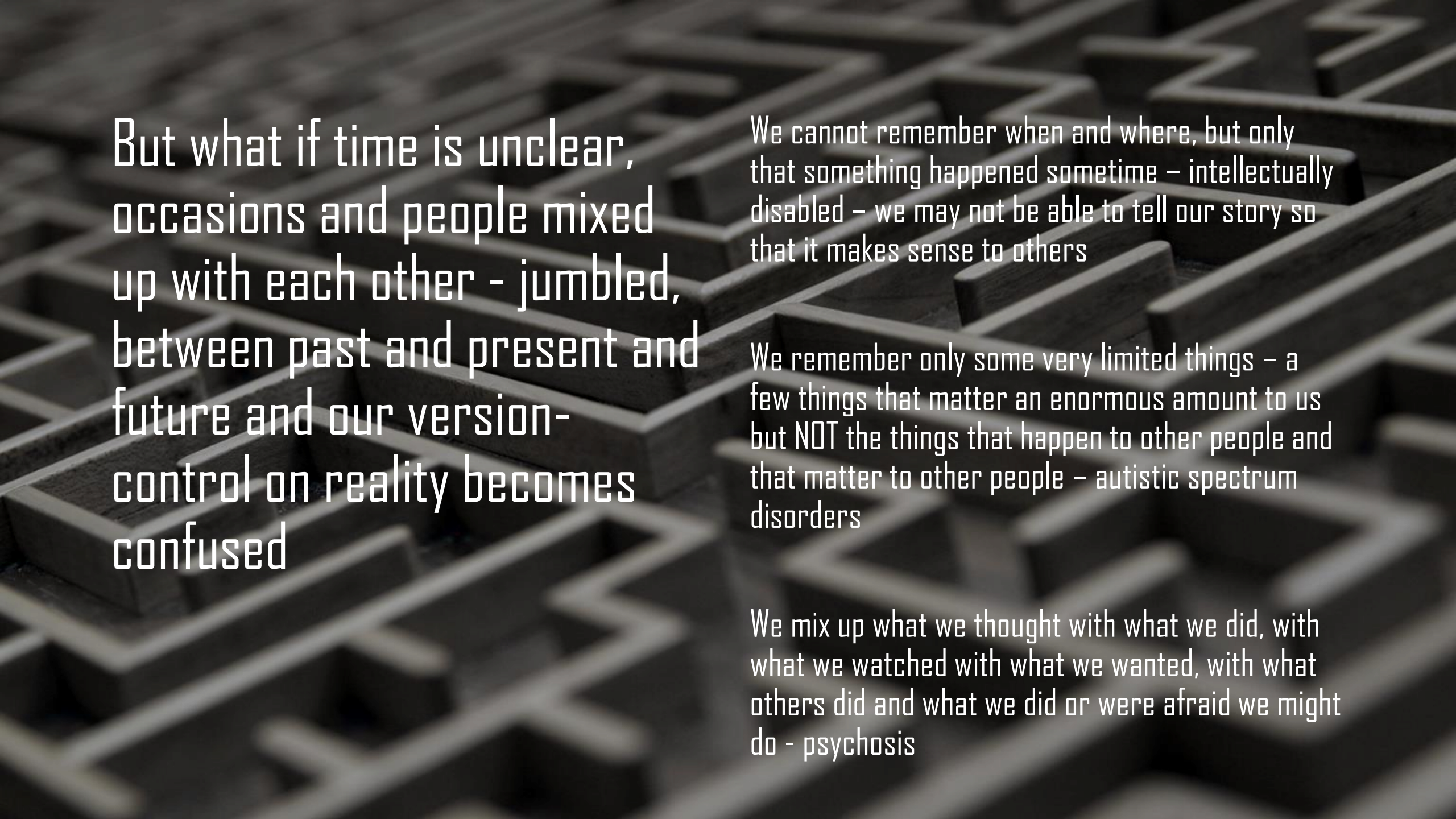


The Retentive Mind – the many forms of memory and time binding – a date stamp

The outside world has been:

- Received by our senses
- Represented in our inner world
- Filtered for risk and benefit
- Reconstructed into a sequence and a story

It is time to have a 'save' mechanism – our memory system - in which the story is put into a particular time and place – **time binding** – date stamping



But what if time is unclear,
occasions and people mixed
up with each other - jumbled,
between past and present and
future and our version-
control on reality becomes
confused

We cannot remember when and where, but only
that something happened sometime – intellectually
disabled – we may not be able to tell our story so
that it makes sense to others

We remember only some very limited things – a
few things that matter an enormous amount to us
but NOT the things that happen to other people and
that matter to other people – autistic spectrum
disorders

We mix up what we thought with what we did, with
what we watched with what we wanted, with what
others did and what we did or were afraid we might
do - psychosis



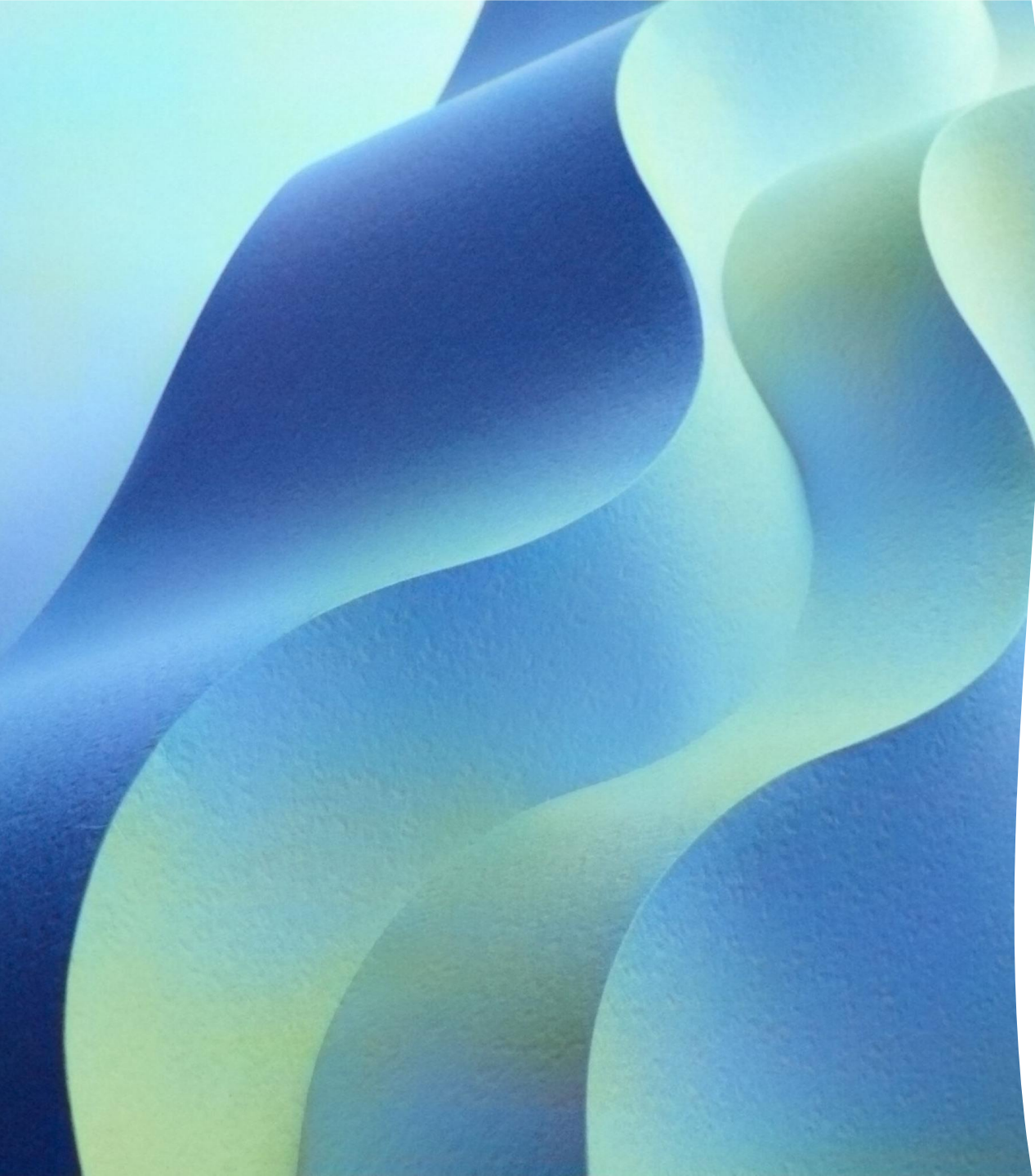
The Responsive Mind – living in the present, remembering the past and adapting to the future

So much has gone into our brains – received to be represented, to be scanned for risk and gain, to be reconstructed into a story, retained and saved to manage the future

But now we must respond to what is needed, wanted, feared and desired – we must act and that includes speaking

We must act in the present with the past and future in mind

We must act in the present to avoid the mistakes of the past and to get the best out of the future – **we must anticipate and adapt**



But if we are bound by the past,
'paralysed' in the present and fearful for
the future – **we act and speak out of
sync**

When we learn slowly, we have to use what we have learned from the past, even if it is no longer relevant – we haven't been able to update our apps – intellectual disability – we act and speak out of sync with the present

We cannot understand the social world around us and communicate the emotional world within us, we are bound to act by our senses not our relationships, by the present, not so much the past, or the future – autistic spectrum disorders – we act and speak out of synchrony with those around us

When past and present and future are jumbled into a time-tumbler, we misinterpret intentions mistrustfully – we may act and speak bizarrely, fearfully, angrily and inappropriately – psychoses



The Recursive Mind

The Body is part of the outside world to the Brain

When the body is in pain the brain treats it like another in-put

When the body moves the brain now has a new set of in-puts

When the mouth speaks the ears listens to its voice

In-put to the brain (sensation) becomes out-put (motor)

But then motor becomes the next in-put for the brain to process

This circular process or feedback loop is called recursiveness



But what happens when feedback the loop is broken

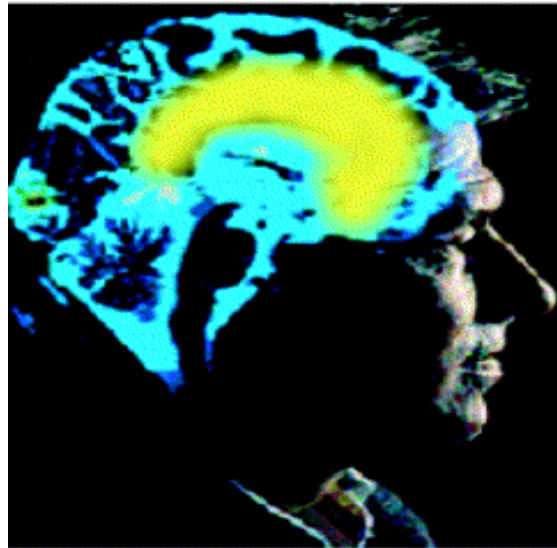
Our body is doing things that we do not know or understand – intellectual disability – we do not understand how our body works in very basic terms

What happens when we have no sense of our space and other people's space, our voice and their voices, their intentions and our own, what we want to do physically and what is appropriate – autistic spectrum disorder

What happens when we mix up the outside world with my body, my body with the outside world, what is caused by me and caused by others and what my body has just done and needs to be about to do - psychosis

Cortical Midline Structures and the Sense of Self

Georg Northoff and Felix Bermphol (2004) Cortical midline structures and the self. *Trends in Cognitive Sciences* 8 (3)102-107



Representation: labelling of stimuli as self-referential

Monitoring of self-referential stimuli

Evaluation: judgment of self-referential stimuli

Integration: linkage of stimuli to the personal context

Self-awareness: awareness and recognition of the own face/body

Unity: experience of the self as a unit

Agency: feeling of being causally involved in an action

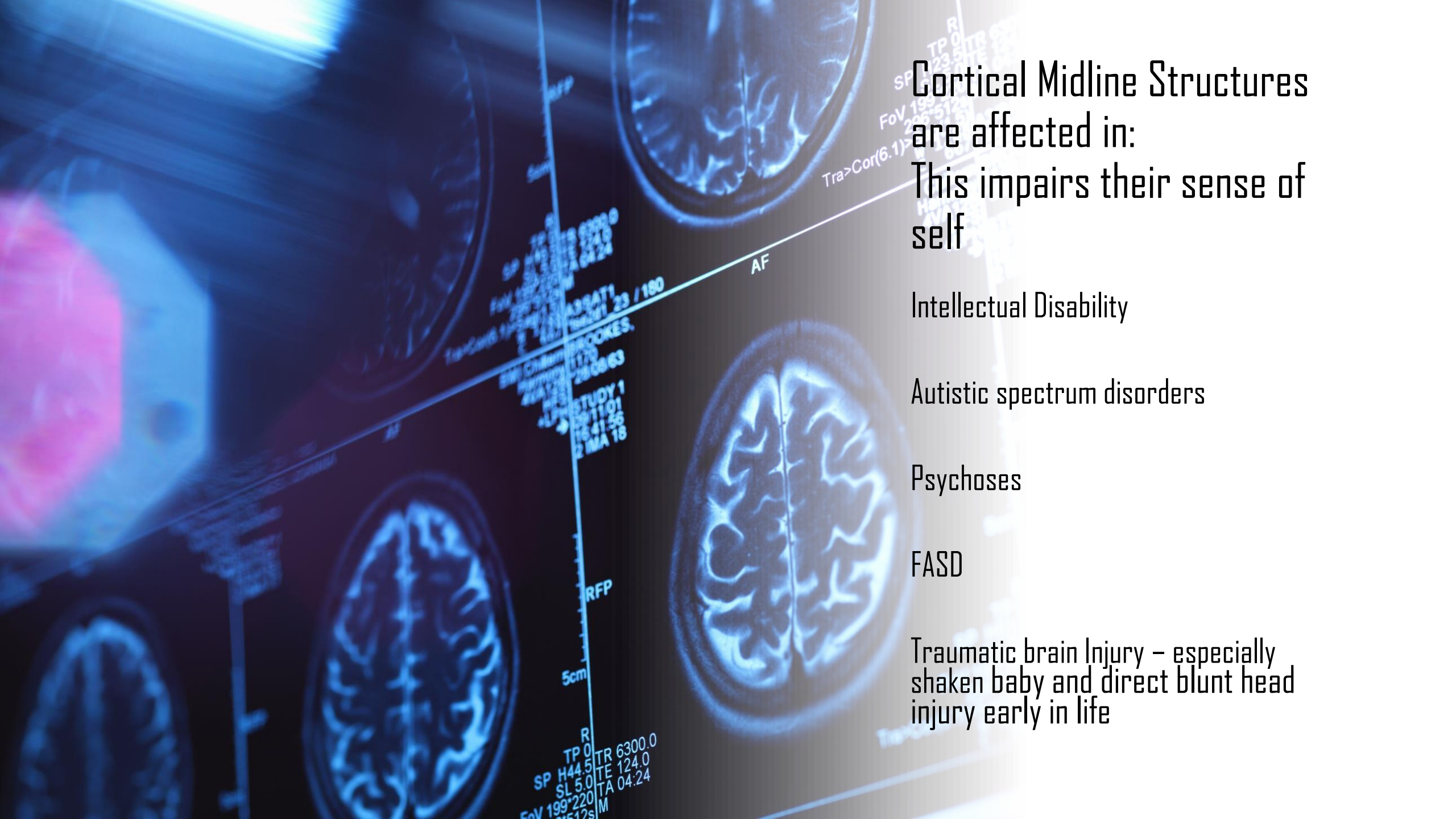
Spatial perspectivity: location of the self in space

Ownership: perceptions of body and environment as self-related

Mind-reading: covert mimicing of others mental states

Emotion: convergence/experience of intero- and exteroceptive stimuli

Autobiographical memory: integration of stimuli in the personal context



Cortical Midline Structures
are affected in:
This impairs their sense of
self

Intellectual Disability

Autistic spectrum disorders

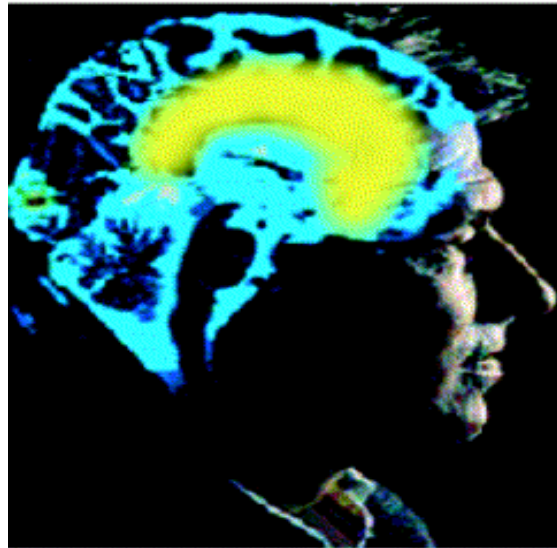
Psychoses

FASD

Traumatic brain Injury – especially
shaken baby and direct blunt head
injury early in life

Cortical Midline Structures and the Sense of Self

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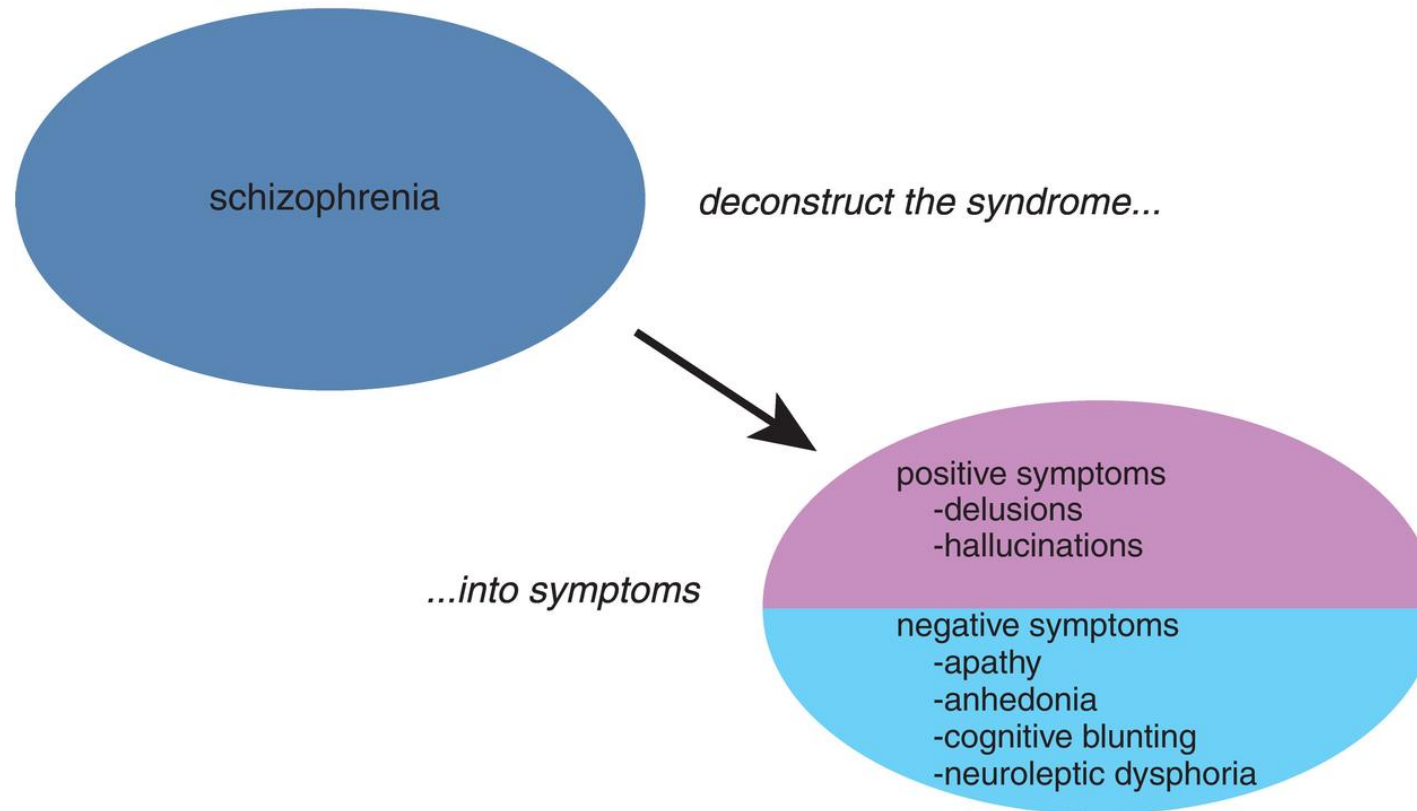
Mind-reading: covert mimicing of others mental states

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Autobiographical memory: integration of stimuli in the personal context

Stahl's Essential Psychopharmacology Cambridge: University Press
This representation is far too simple when it comes to ID, ASD and ADHD

Schizophrenia: The Phenotype



A Convergence of Adversity

The earlier the onset

The more severe

The larger the
communication difficulty

The greater and the
longer the stress
(expectational, illness
and traumatic)

The less the support

**The more likely they
are to converge and
all three to occur
together**

Mild plus mild plus mild



Mild Adaptive Impairment

Moderate intellectual disability

+

Moderate Social Disability



MODERATE
ADAPTIVE
IMPAIRMENT

+

Moderate Psychotic Symptoms

One plus one plus one



ONE

A global mild for multiple disabilities often means a moderate ($1/3 - 1/2$ age equivalents) in amount of support needed

When there is an earthquake, who is measuring how much rain is falling?

All severe to profound intellectually disabled are severely socially and communicatively impaired and therefore on the autistic spectrum at the severe end

All severely and profoundly socially impaired autistic young people cannot communicate adequately to confirm, or disconfirm, whether they have hallucinations or delusions

But they do have the same inabilities as psychotic young people – sometimes more and sometimes less and often worse around and after puberty

All psychotic young people are impaired intellectually and socially at some times, often severely so, but can recover from their disability, more or less

How to make someone more disabled and therefore to push them towards multi-disability function including psychosis

Place them under multiple demands simultaneously

Create time pressure – 'hurry up!'

Ask them to do something they are mostly not capable of

Criticize them while they are doing it

Tell them what their doing wrong in loud, irritated tone of voice

Tell them what **NOT** to do

Add a social dimension such as 'spotlighting', bullying or humiliation

Don't make it clear what you are saying or want

Don't give them a sequence or a story – just a command

Ask them to hold instructions, multiple instructions, in their head

When things go wrong tell them it is their fault

Is it a coincidence, a confusion or a thing?"

The figures are too high to be just a coincidence – two rare disorders, let alone three should be much rarer occurring together by chance

Eg: Say Intellectual disability + Autistic spectrum disorder + Psychosis

Probability of random co-occurrence in adolescence

= $1/50 \times 1/40 \times 1/50 = 1/100,000$ which means each year another child should be added to the group and there would be a maximum of 5-10 children in New South Wales at any given time < 18 years of age. We know the numbers are very much higher.



Is it a coincidence, a confusion or a thing?"

My own estimate of all three together in adolescence is approx.

1/250 peri and post pubertally ie 400 -500 new cases per year and 2,000 cases in NSW at any one time

It is not a coincidence



Confusion?

Almost all the issues of

Overshadowing

Communication difficulties

Poor definition of criteria

Will suggest increasing the numbers not reducing them

The confusion reduces the apparent size of the problem

Three Brain Disorders - Are they connected?

ID - Does difficulty learning, remembering and solving problems

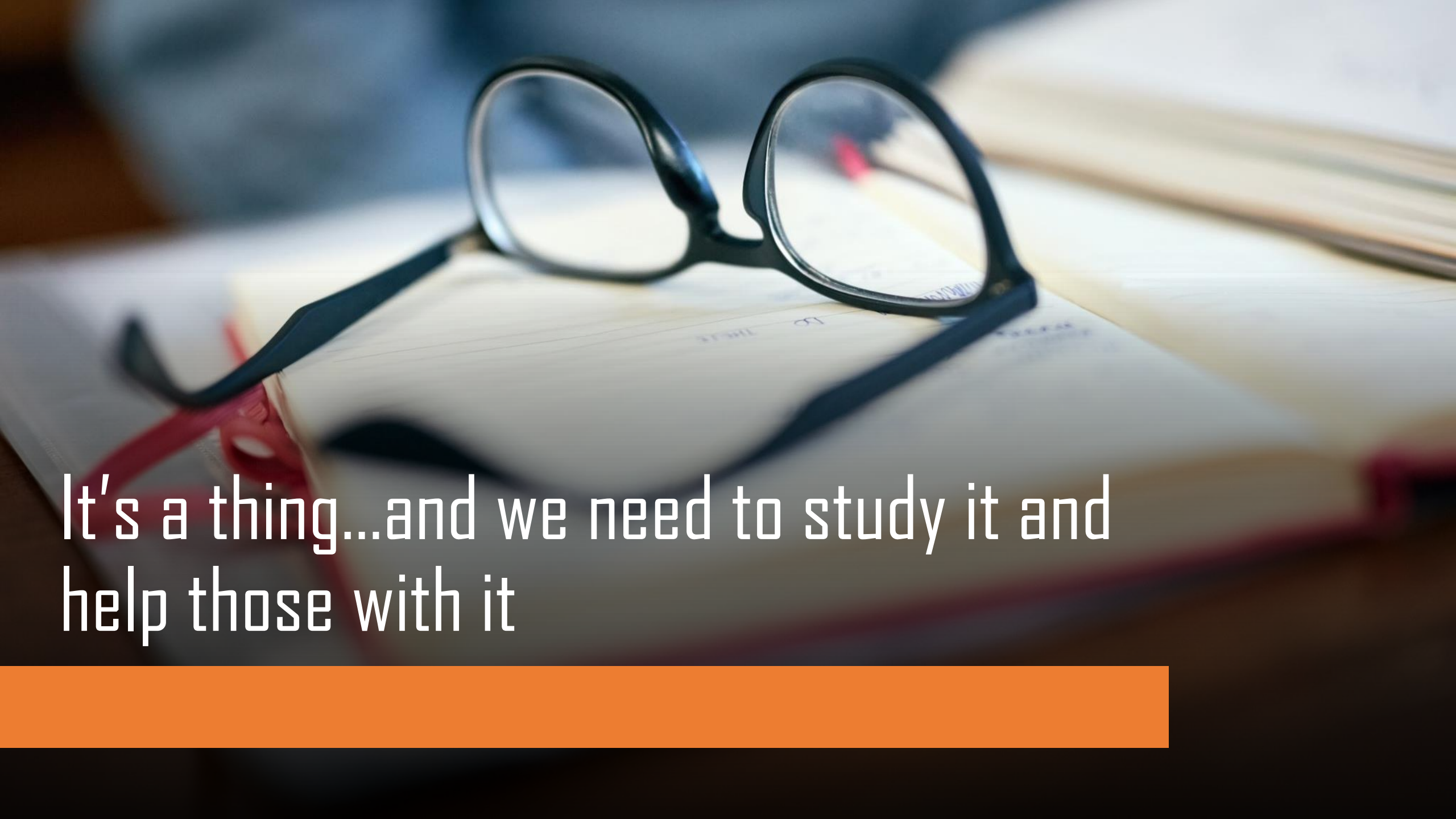
Make it **more likely** to have

ASD - difficulty relating, communicating and dealing with social situations?

Does having ID and ASD make it **more likely** to have

Psychosis Spectrum - difficulty making sense, trusting and telling what is real and not real - 'holding it all together' ?





It's a thing...and we need to study it and help those with it



References:

Vera A. Morgan, Helen Leonard, Jenny Bourke and Assen Jablensky **Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study** The British Journal of Psychiatry (2008) 193, 364–372.

- Schizophrenia, but not bipolar disorder and unipolar depression, was greatly over- represented among individuals with a dual diagnosis: depending on birth cohort, **3.7–5.2% of those with intellectual disability had co-occurring schizophrenia.**

Ribolsi M, Fiori Nastro F, Pelle M, Medici C, Sacchetto S, Lisi G, Riccioni A, Siracusano M, Mazzone L and Di Lorenzo G (2022) **Recognizing Psychosis in Autism Spectrum Disorder.** Front. Psychiatry 13:768586.

- **There is strong evidence for the existence of a high comorbidity between autism and psychosis with percentages reaching up to 34.8%** and several significant implications for treatment and prognosis of these patients. However, the identification of comorbid psychosis in patients with Autism Spectrum Disorder represents a complex challenge from a psychopathological point of view, in particular in patients with greater deficits in verbal communication. Intercepting the onset of a psychotic breakdown in autism may be very difficult, both disorders in fact occur along a phenotypic continuum of clinical severity and in many cases, psychotic symptoms are present in an attenuated form.

Zablotsky B, Black LI, Maenner MJ, Schieve LA, Danielson ML, Bitsko RH, Blumberg SJ, Kogan MD, Boyle CA. **Prevalence and Trends of Developmental Disabilities among Children in the US: 2009–2017.** *Pediatrics.* 2019; 144(4):e20190811

Main Findings:

During the study period (2009–2017)

About 1 in 6 (17%) children aged 3–17 years were diagnosed with a developmental disability (includes cerebral palsy, ADHD, blindness and deafness), as reported by parents;

In the study population, some groups of children were more likely to have been diagnosed with a developmental disability than others, such as:

- Boys compared to girls;

- Non-Hispanic white and non-Hispanic black children compared to Hispanic children or non-Hispanic children of other races;

- Children living in rural areas compared to children living in urban areas; and

- Children with public health insurance compared to uninsured children and children with private insurance.

The percentage of children aged 3–17 years diagnosed with a developmental disability increased—from 16.2% in 2009–2011 to 17.8% in 2015–2017.

Specifically, diagnoses increased for attention-deficit/hyperactivity disorder (ADHD) (8.5% to 9.5%), autism spectrum disorder (ASD) (1.1% to 2.5%), and intellectual disabilities (ID) (0.9% to 1.2%).*

References:

Psycho-educational groups for people with a dual diagnosis of psychosis and mild intellectual disability: A preliminary study

Valerie Crowley, John Rose, Jo Smith, Kate Hobster and Eleanor Ansell *Journal of Intellectual Disabilities* 2008 12: 25

Bramston, P., Fogarty, G. and Cummins, R. 1999. The nature of stressors reported by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 12(1): 1-10.

Doyle, C. and Mitchell, D. 2003. PTSD and people with learning disabilities: A literature based discussion. *Journal of Learning Disabilities*, 7(1): 23-33.

Mevisen, L. and de Jongh, A. 2010. PTSD and its treatment in people with intellectual disabilities: A review of the literature. *Clinical Psychology Review*, 30: 308-316.

Reiss, S., Levitan, G. W. and Szyszko, J. 1982. Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency*, 86: 567-574.

Stenfert-Kroese, B. and Thomas, G. 2006. Treating chronic nightmares of sexual assault survivors with an intellectual disability: Two descriptive case studies. *Journal of Applied Research in Intellectual Disabilities*, 19: 75-80.

Mild

- 85% of ID Population
- Can generally learn reading, writing, and math skills between third- and sixth-grade levels. May have jobs and live independently.

Moderate

- 10% of ID Population
- May be able to learn some basic reading and writing. Able to learn functional skills such as safety and self-help. Require some type of oversight/supervision.

Severe

- 5% of ID Population
- Probably not able to read or write, although they may learn self-help skills and routines. Require supervision in their daily activities and living environment.

Profound

- 1% of ID Population
- Require intensive support. May be able to communicate by verbal or other means. May have medical conditions that require ongoing nursing and therapy.