

Disaster Recovery and Resilience

Considering autism in crisis response and recovery

Thursday 18 April 2024



Australian Government




An Australian Government Initiative

CITY OF
GOLDCOAST.

Gold Coast Health
always care



Queensland
Government



**'We begin today by acknowledging the Traditional Custodians of the land on which
we
gather today.**

**We acknowledge the waterways, the land, the sky and all who
inhabit this country.**

**We acknowledge their ancestors, and Elders and recognise those who continue to
protect and promote Aboriginal and Torres Strait Islander cultures.**

We acknowledge the past and unite for our future.



WHO IS JENNIFER ALTHAUS?

- CEO of Orange Elephants Creative Minds
- Mother of two autistic children (26 and 16 year)
- Experienced the Gold Coast February 2022 floods
- Author : A Journey of Love, A mother's memoir, Bored! Bored! Bored! (picture book) and Life in Learning, Learning is Life Unschooling Journal
- Started my career in early childhood
- Trained as a Child Safety Officer working with Aboriginal Communities in Mt Isa
- Bachelor of Arts (Creative Writing and Criminal Justice)
- Graduate Certificate in Autism Studies
- Higher Degree in Research: Masters in Education and Professional Studies Research



Orange Elephants Creative Minds

ORANGE ELEPHANTS CREATIVE MINDS

- Officially started in 2020
- Provide services and programs for autism, co-occurring disabilities and complex cases.
- Home visits, online programs and in office consultations,
- Support Coordination, bibliotherapy, writing therapy, mentoring, life skills, academic tutoring, social groups, African Drumming therapy, Lego therapy...
- Training and keynote speaking - support workers, allied health workers, corporate business, families..



You Are Not Alone!
Autism Helpline



Free Helpline 8am-10pm 7 days week
ph/txt: 0432 010 880

Neuro-Affirming advice, support and
advocacy for individuals, families,
medical teams and other professionals.
Specialising in criminal justice support
and complex cases

Face to face consultation available at cost by appointment.
Call out charge for short notice visits
Gold Coast only

info@orangeelephantscreativeminds.com.au
www.orangeelephantscreativeminds.com.au

Rural Outreach Program

Linking outback Australia to neuro-affirming services for autism, co-occurring conditions and complex cases.



Private Consultation
Staff training
Workshops
Keynote Speaking

Specialising in Executive
Functioning, Youth and Criminal
Justice.

info@orangeelephantscreativeminds.com.au

M:0432010880

Group Activity

Introduce yourself to your neighbour.

Tell them one thing you know about autism.

As a group we will take turns to introduce our neighbour to everyone



**“In order to support we
must first understand”**



OVERVIEW

What is Autism?

- How is autism diagnosed?
- Levels of ASD
- Comorbid Disorders
- Co Occurring Issues
- Social Communication
- Social Interaction
- Restrictive and Repetitive Behaviours
- Sensory Sensitivity

So what does all this mean in a crisis?

- My story
- Discussion - how would my situation effect an autistic individual.
- Things to consider
- Possible outcomes
- How we can make things easier
- Moving forward. How can we improve?

Please ask questions at any time.

WHAT IS AUTISM ?

Also known as Autism Spectrum Disorder or ASD

- A neurological disorder
- A developmental disorder - symptoms generally appear in the first 2 years of life.
- It affects how people interact with others, communicate, learn and behave.
- It is a spectrum (Autism Spectrum Disorder) - wide variation severity.
- It often presents with comorbid and co-occurring disabilities.



AUTISM IN AUSTRALIA

It is estimated 1 in 70 Australians are on the autism spectrum

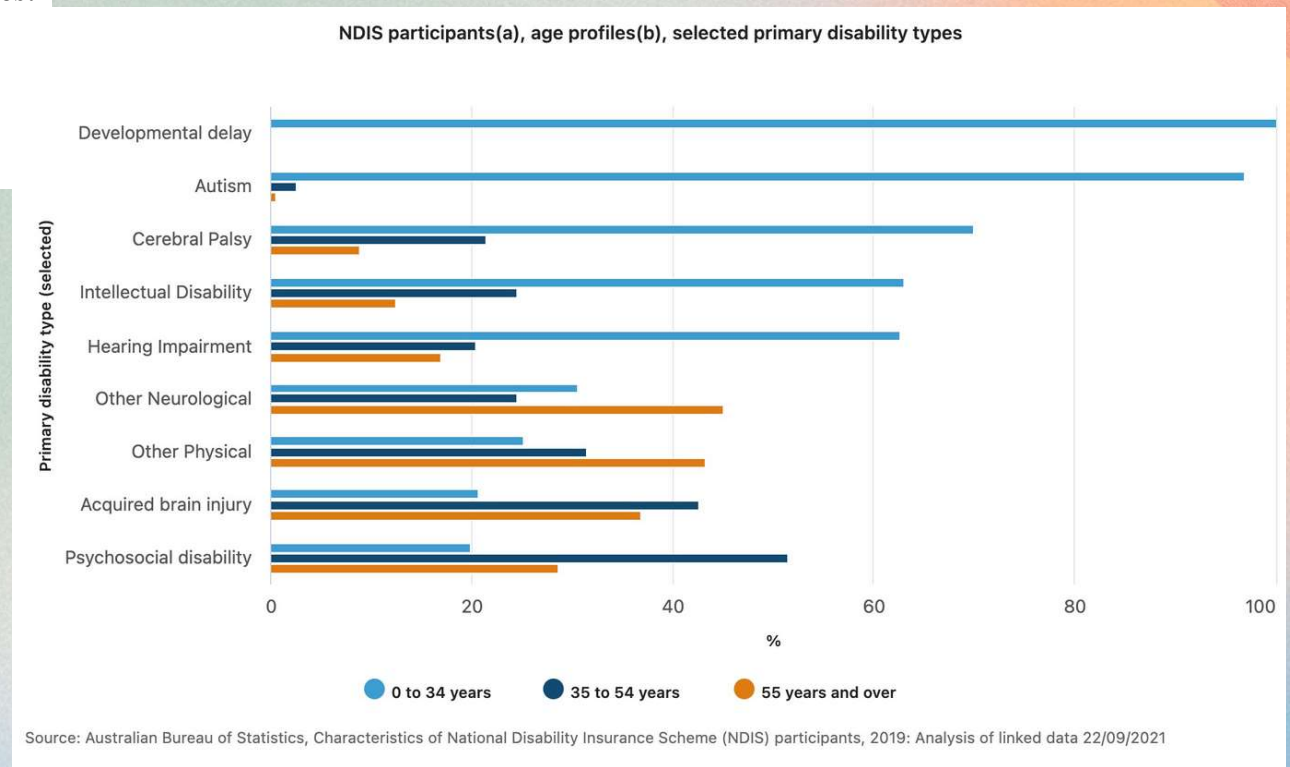
In 2018:

- there were 205,200 Australians with autism, a 25.1% increase from the 164,000 with the condition in 2015.
- males were 3.5 times more likely than females to have the condition, with prevalence rates of 1.3% and 0.4% respectively.
- The unemployment rate for people with autism spectrum disorders was 34.1%, more than three times the rate for people with disability (10.3%) and almost eight times the rate of people without disability (4.6%).
- among all people with autism, 68.9% (141,400) reported having a profound or severe core activity limitation - supervision with communication, self-care and mobility.
- 92.3% of young people (101,900) aged 5 to 20 years on the autism spectrum attending school had some form of educational restriction (92.3%). Two in five (40.8%) attended a special class in a mainstream school or a special school.
- Of the young people (aged 5 to 20 years) who were attending school or another educational institution, 77.7% reported experiencing difficulty. The main problems encountered - fitting in socially (59.8%), learning difficulties (55.3%), communication difficulties (51.5%).

NDIS Statistics

Most common primary disability types:

- autism (30.9% of all participants)
- intellectual disability (20.2%)
- psychosocial disability (9.1%)



HOW IS AUTISM DIAGNOSED?

- Classified under DSM -5 (primary system used in Australia for identifying mental health conditions). Came into use in 2013.
- DSM - 5 - TR - update of DSM - 5 in 2022 - a shift toward inclusivity and greater acceptance including levels should not be used to decide whether individuals are eligible for services.
- By one health professional - paediatrician or a psychiatrist or psychologist - if there is obvious signs.
- By a multidisciplinary team - paediatrician, psychologist and speech therapist - necessary for children with less clear symptoms or who have other conditions that make the diagnosis more complicated.

Assessment tools:

- The Child Autism Rating Scale (CARS)
- The Autism Diagnostic Observation Schedule (ADOS)
- Autism Detection in Early Childhood (ADEC)
- The Autism Diagnostic Interview – revised (ADI-R)
- The Social Communication Questionnaire (SCQ).



DSM-5

- **Persistent deficits in social communication and social interaction - must have deficits in all areas.**
- **Restricted and repetitive patterns of behaviour, interests or activities - must have deficits in at least 2 in this area.**
- **Deficits must be present in the early development period (may not fully manifest until social demands meet limited capacities, may be masked later in life by learned strategies)**
- **Symptoms must cause significant impairment in social, occupational or life functioning.**
- **Deficits must not be better explained by intellectual development or global developmental delay**



American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.)

DSM - 5 Diagnostic Criteria

Social Communication and Social Interaction	Restricted, Repetitive Patterns of Behaviour
<p>1. Deficits in social-emotional reciprocity.</p> <ul style="list-style-type: none"> • abnormal social approach and failure of normal back-and-forth conversation, • reduced sharing of interests, emotions, • failure to initiate or respond to social interactions. 	<p>1. Stereotyped or repetitive motor movements, use of objects, or speech.</p> <ul style="list-style-type: none"> • Simple motor stereotypies, • Lining up toys, • Flipping objects, • Echolalia, • Idiosyncratic phrases.
<p>2. Deficits in nonverbal communicative behaviours used for social interaction.</p> <ul style="list-style-type: none"> • poorly integrated verbal and nonverbal communication, • abnormalities in eye contact and body language, • deficits in understanding and use of gestures, • a total lack of facial expressions or nonverbal communication. 	<p>2. Insistence of sameness, inflexible adherence to routines and ritualised patterns of verbal or nonverbal behaviour.</p> <ul style="list-style-type: none"> • Extreme distress at small changes, • Difficulties with transitions, • Rigid thinking patterns, • Need to eat same food each day, • Need to take same route each day, • Greeting rituals.
<p>3. Deficits in developing, maintaining, and understanding relationships.</p> <ul style="list-style-type: none"> • difficulties adjusting behaviour to suit various social contexts, • difficulties in sharing imaginative play, • difficulties in making friends, • absence of interest in peers. 	<p>3. Highly restricted, fixated interests that are abnormal in intensity or focus.</p> <ul style="list-style-type: none"> • Strong attachment to or preoccupation with unusual objects. • Excessively circumscribed or perseverative interests.
	<p>4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment.</p> <ul style="list-style-type: none"> • Apparent indifference in pain/temperature, • Adverse response to specific sounds or textures, • Excessive smelling or touching of objects, • Visual fascination with lights or movement

Severity Levels for ASD

Severity Level for ASD	Social Communication	Restricted interests & repetitive behaviours
Level 3 - 'Requiring very substantial support'	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others	Preoccupations, fixated rituals and/or repetitive behaviours markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.
Level 2 - 'Requiring substantial support'	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others	RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest
Level 1 - 'Requiring support'	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions	Rituals and repetitive behaviours (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest.

COMORBID DISORDERS

- Attention Deficit Hyperactivity Disorder (ADHD)
- Obsessive-compulsive Disorder (OCD)
- Sensory Processing Disorder
- Intellectual Impairment
- Developmental Coordination Disorder
- Anxiety
- Depression
- Bipolar
- Schizophrenia/Psychosis
- Addiction
- Epilepsy
- Functional Neurological Disorder
- Gastrointestinal Conditions - constipation, chronic diarrhoea, reflux, bloating, colitis, inflammatory bowel disease, food intolerance
- Genetic Disorders - Down Syndrome, Muscular Dystrophy, Fragile X Syndrome,
- Hydrocephalus
- Cerebral Palsy
- Migraine/headaches
- Sleep Disorders
- Gender Dysphoria
- Ehlers-Danlos Syndrome
- Hyper-mobility Spectrum Disorder
- Tourette Syndrome
- Phobias
- Eating disorders - Bulimia, anorexia



CO-OCCURRING ISSUES

Life experiences or events that may be exacerbated by Autism:

- Homelessness
- Disruption to or non attendance at school - poor academic achievement
- Unemployment
- Relationship breakdowns
- Crime - delinquent behaviour
- Drugs and alcohol
- Bullying
- Challenging behaviours - fighting, verbal abuse
- Negative repercussions on general health
- Impact on mental health - low self-esteem, low self-worth, panic disorders, phobias, anxiety, high level stress
- Exclusion from social events
- Dysregulated anger
- Feelings of loneliness
- Poverty



SOCIAL COMMUNICATION

- Difficulty holding a conversation.
- Difficulty with eye contact.
- Difficulty understanding facial expression - they are not rude, uninterested or inattentive.
- Difficulty understand non-verbal cues - body language.
- May be non-verbal - use sign language or electronic aids.
- May use gestures to get their message across - pointing, taking you to something.
- May have good memories - short term or long term.
- May be able to read at an early age or may not be able to read at all.
- May have auditory processing issues - for some it takes longer to process what you have said.
- May use repetitive or rigid language - echolalia, high pitched voice, starting sentence with repetitive phrase.
- May have sensory issues - room too loud, bright, smells wrong. Smell of perfume.

SOCIAL INTERACTION

- Difficulty recognising and understanding social cues - how to approach others, how to play as a team.
- Difficulty adjusting their behaviour to different situations - this is not instinctively learnt.
- Difficulty understanding social barriers.
- May take longer to respond to verbal communication in a social setting.
- May display odd behaviour that is hard for others to understand - may not be age appropriate.
- Sensory stimuli may make social interaction harder.
- May overshare or under share their interests.

RESTRICTIVE AND REPETITIVE BEHAVIOURS

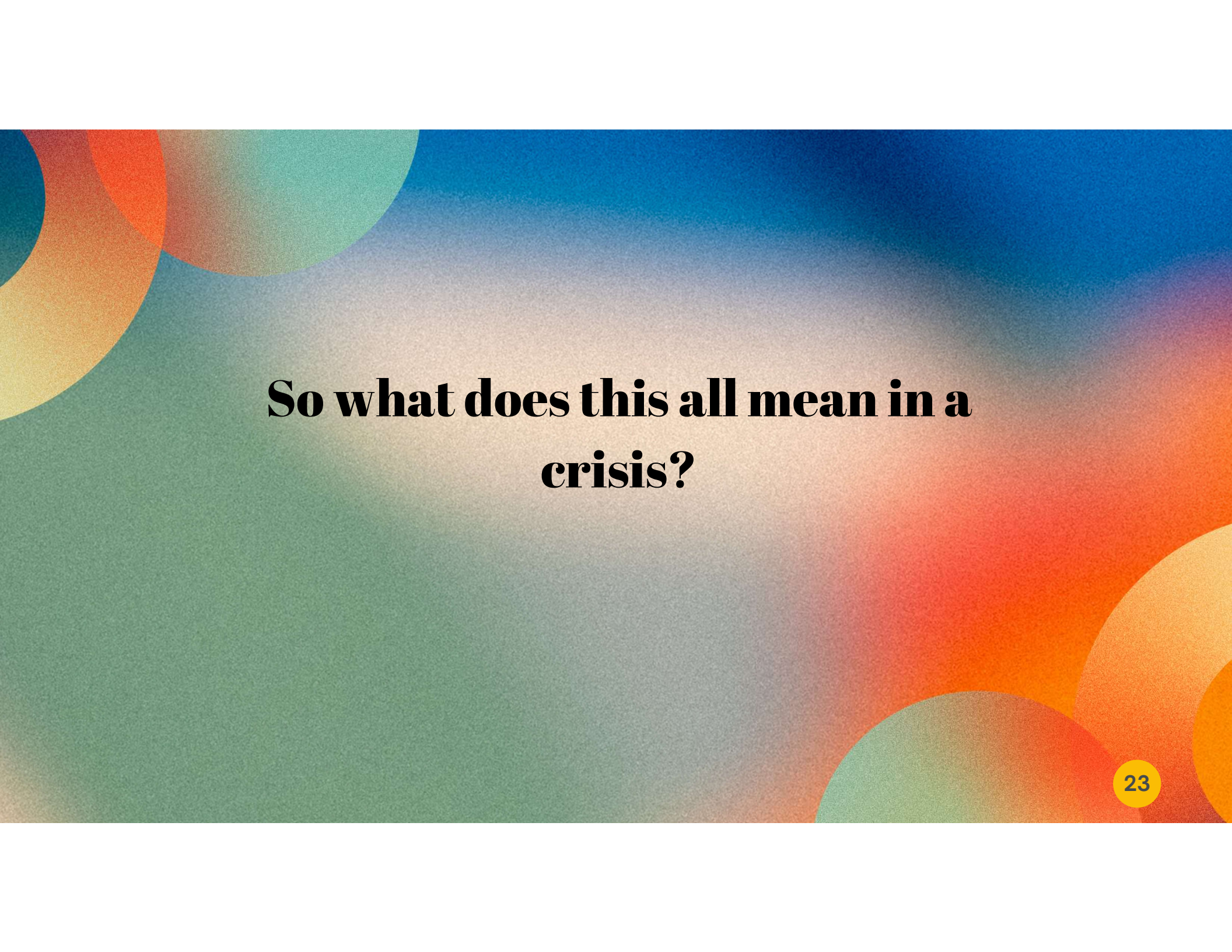
- Stereotyped or repetitive motor movements.
- Stereotyped or repetitive use of objects.
- Repetitive use of speech.
- Insistence of sameness, inflexible adherence to routines.
- Ritualised patterns of verbal or non verbal behaviour.
- Highly fixated interests that are atypical in intensity or focus.
- Can be distracting but can also be a strength.
- Some behaviours may offer calming effect.



SENSORY SENSITIVITY

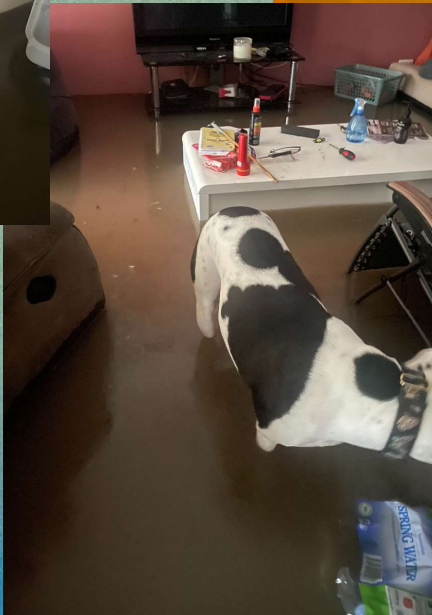
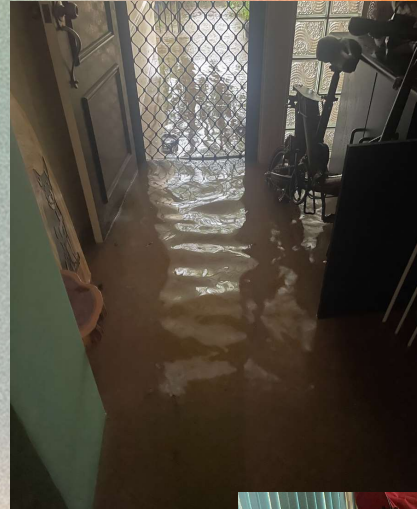
- Hyper-sensitive - extreme sensitivity.
- Hypo - sensitive - under responsive.

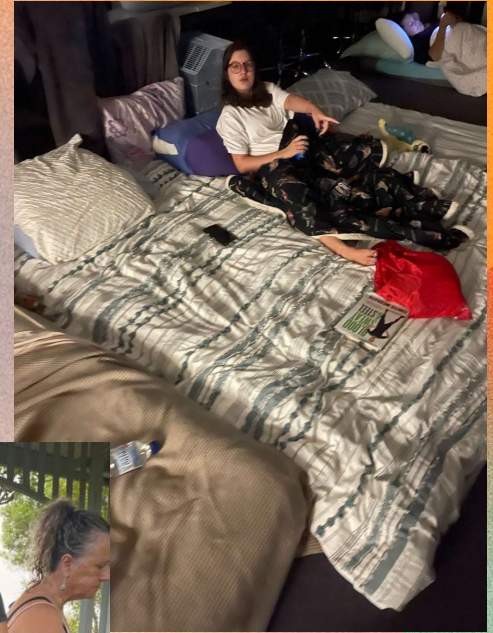




**So what does this all mean in a
crisis?**

February 2022 Floods













How would the situations you just heard about affect an autistic individual?

Things to consider:

- Sensory changes (hyper or hypo sensitivity)
- Changes in routine (difficulty adapting, requires sameness)
- Surrounded by people they do not know
- Food availability
- Difficulty with social cues
- Environmental surroundings
- May not have medications
- Restrictive and repetitive behaviours
- Anxiety and stress (including that of the family/carer)
- Possibly being cut off from family/friends/regular supports

Possible Outcomes

- Stimming - headbanging, repetitive movement, repetitive sound
- Meltdown - lying on ground, may curl in fetal position, may become disorientated, may scream or become verbal or physically aggressive.
- May become anxious - this may lead to repetitive speaking such as asking the same question over and over.
- May require time out - somewhere to be alone.
- May have difficulty comprehending what is being said to them and reading expressions and body cues of others.
- Decision making may become difficult.
- Difficulty access required support and services.
- If previously verbal may become unable to talk.



How can we make things easier?

- Educate ourselves on autism and recognise it. Is there indication around the room the individual may be autistic?
- Stay calm (limit additional noise and sensory input)
- Introduce yourself. Why are you there? What are you going to do, why, how?
- Ask others to limit noise - turn off sirens and flashing lights.
- Ask the individual how you can help them.
- Give time to answer (considering auditory processing delay?)
- Listen to family/carers - they know the needs of the autistic person well.
- Break instruction down - one step at a time.
- Notice YOUR environment - is the individual holding something or wearing a particular shirt you may be able to comment on. Engage in their world. Show interest in them not the situation.
- DO NOT touch the individual without telling them prior to doing so. This includes a simple touch on the shoulder, back or arm to direct them.
- Look for a quiet place you can direct them to in order to alleviate sensory stimuli.
- Ask them what they need to take with them - accept that what you think is not important may be to them.
- Limit interaction - allocate one person to care for the individual.
- **Respect their property, space and requests.**

Moving forward: How can we improve?

- Education for first responders, SES, Volunteers, Allied Health Teams and all involved in disaster recovery.
- Autism specialist first responder team who can be called when required - this would allow other responders to get on with other tasks.
- Consideration of special needs when planning evacuation shelters - quiet room, somewhere to change adult diapers...
- Signs on homes/rooms to help first responders identify the special needs of the occupant.
- Education of the importance of an evacuation box/bag clearly marked for easy access to requirements during a crisis.
- List of contact details easily accessible in a crisis.
- Visual aids and social stories to help assist the individual understand what is happening and who can help.

Thank you for attending and participating
Your feedback is important to us.

**Considering Autism in Crisis
Response and Recovery**



Google reviews appreciated

