Behaviours of Concern

in young people with intellectual disability

NSW GOVERNMENT | Health

Acknowledgment of Country

We acknowledge that we are hosting this webinar from the land of the Bedegal peoples, and also acknowledge the Traditional Custodians of the lands on which you are all joining us from today.

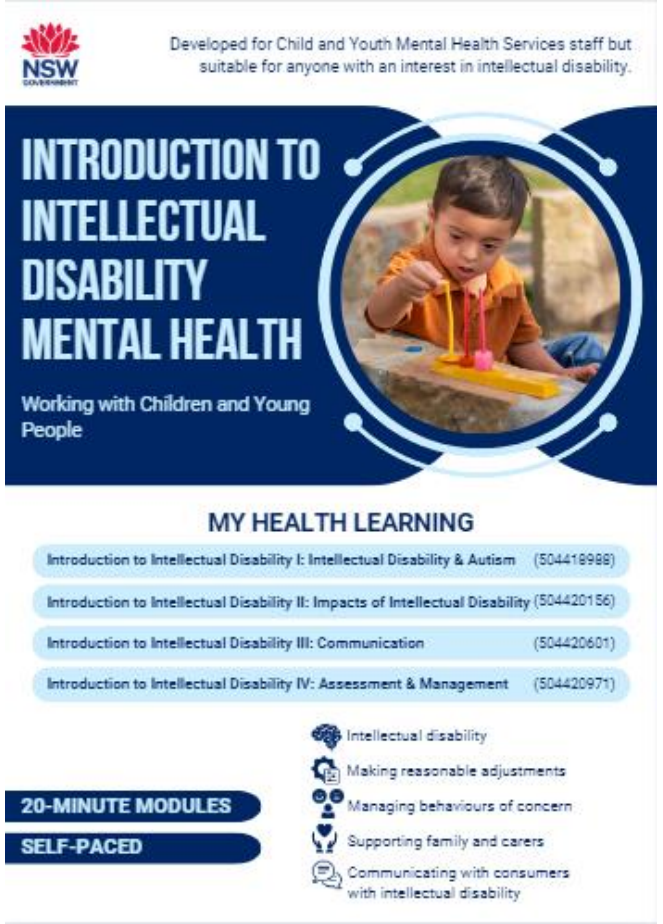
We pay our respects to Elders both past and present and extend that respect to other First Nations peoples across Australia.

Introduction

Intellectual Disability Mental Health Training

Aimee Blackam

Principal Policy Officer
Disability and Social Policy
Mental Health Branch
Ministry of Health



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Presenters

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Overview

Introduction

Assessment and collaboration

Aggression and self-harm

De-escalation and harm minimisation

Pharmacology

Assessment and collaboration

Photo by Marina Shatskih on Unsplash

All Behaviour is Communication

Photo by Morgan Basham on Unsplash

What are Behaviours of Concern?

‘Behaviours that:

- Create barriers to children’s participation in the community
- Undermine children’s rights, dignity or quality of life
- Pose a risk to the child’s safety or the safety of people are around them.’

Australian Institute of Family Studies, 2024

‘Challenging, complex, or unsafe behaviour that requires more persistent or intensive intervention. It does not include low-level, developmentally appropriate behaviours, such as testing boundaries and rules.’

NSW Department of Education, 2022

‘Behaviours of such intensity, frequency or duration that the physical safety or emotional wellbeing of the child, or others around them, is at significant risk (beyond what is usually expected for the child’s developmental stage).’

NSW Department of Communities and Justice

Hierarchical Assessment

Medical

Psychiatric

Functional

Photo by Patty Brito

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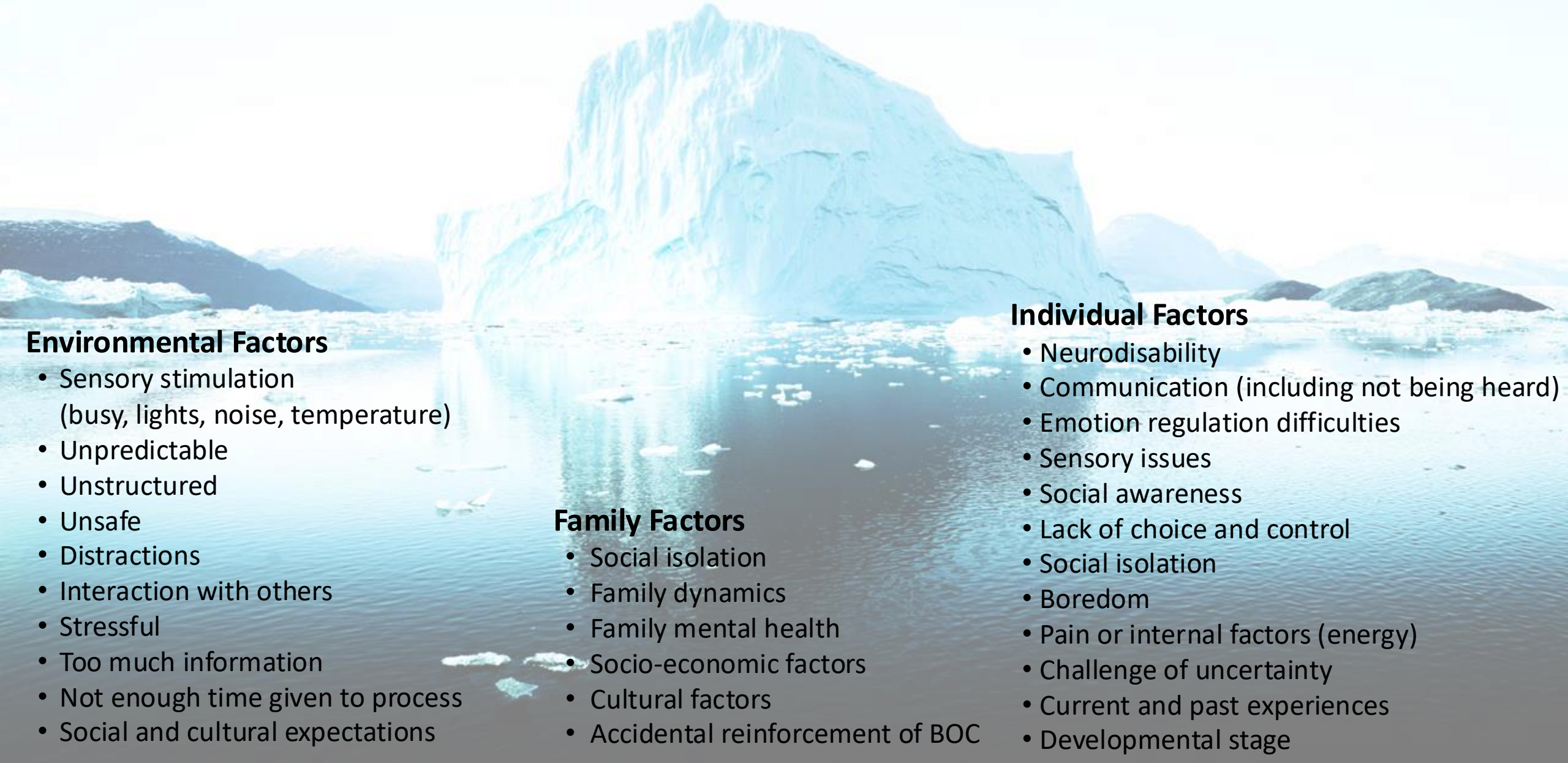
Contributing Factors and Underlying Causes



Environmental Factors

- Sensory stimulation (busy, lights, noise, temperature)
- Unpredictable
- Unstructured
- Unsafe
- Distractions
- Interaction with others
- Stressful
- Too much information
- Not enough time given to process
- Social and cultural expectations

Family Factors

- Social isolation
- Family dynamics
- Family mental health
- Socio-economic factors
- Cultural factors
- Accidental reinforcement of BOC

Individual Factors

- Neurodisability
- Communication (including not being heard)
- Emotion regulation difficulties
- Sensory issues
- Social awareness
- Lack of choice and control
- Social isolation
- Boredom
- Pain or internal factors (energy)
- Challenge of uncertainty
- Current and past experiences
- Developmental stage

Functional Behaviour Assessment

Why is the behaviour occurring?

- Setting conditions
- Triggers
- Maintaining factors

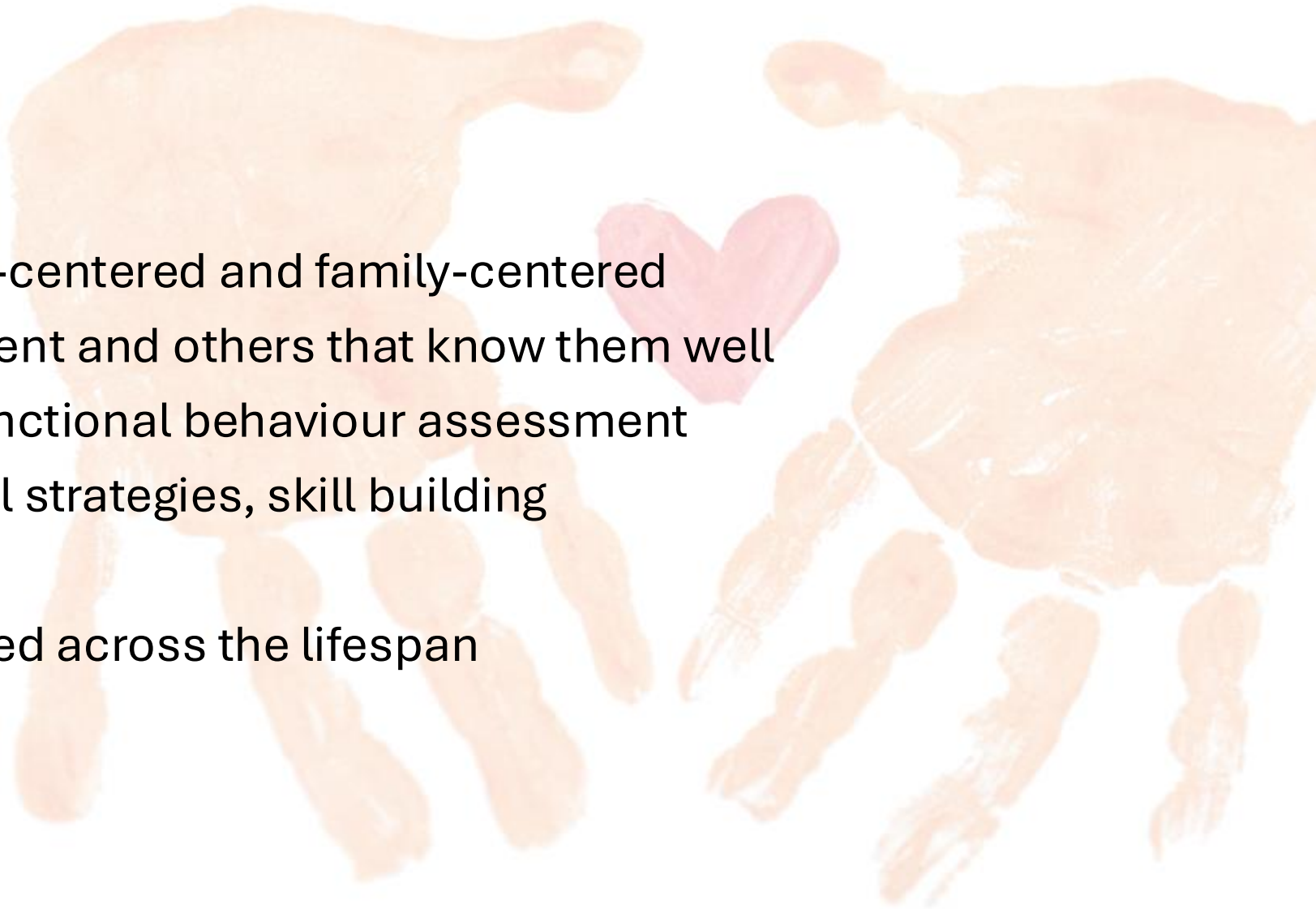
Behaviour is communication

- How are they feeling?
- What need is not being met?
- What do they want to get / get away from?
- How do we know?
- Who can we ask to find out more?
- How can we validate their experience?

Source: Autism Spectrum Australia

Positive Behaviour Support Framework

- Human Rights
- Improving quality of life
- Strengths-based, person-centered and family-centered
- Collaborative – child, parent and others that know them well
- Data-driven, including functional behaviour assessment
- Pro-active, environmental strategies, skill building
- Response plan
- Implemented and reviewed across the lifespan



Positive Behaviour Support Process and Plans

NDIS Quality and Safeguards Commission

(Prompt) Additional guidance and instructions for use are offered throughout the template. Delete these prompts prior to finalising the Comprehensive Behaviour Support Plan.

Comprehensive Behaviour Support Plan

CONFIDENTIAL

Person details

Person's name:		NDIS Participant #:	
Date of Birth (age):		Gender:	
Address:		State or Territory:	

Plan dates

Comprehensive BSP date:		BSP Review date:	

Practitioner and provider details

NDIS Behaviour Support Practitioner:		Contact details:	
Specialist Behaviour Support Provider:		Registration ID:	

Contents

Purpose

The purpose of this Comprehensive Behaviour Support Plan is to:

- Respect and uphold the person's rights **and dignity**.
- **Improve quality of life** and support progress towards positive change.
- Provide **detailed and holistic information about the person** with disability and their needs.
- Provide **person-centred, proactive and evidence-informed strategies** such as environmental changes and skill development to improve overall quality of life, self-determination and **address the underlying function(s)** of the person's behaviour.
- Provide **response strategies** to keep the person and others safe.
- Where relevant, **identify any regulated restrictive practices** used and how they will be reduced and eliminated. Note restrictive practices should **only be used as a last resort** and may not be necessary to minimise the risk of harm.

Figure 5: Behaviour Support Process

'We can't come in with a magic wand and quick fix to instantly fix the perceived problem. It's building those relationships with the families we're working with and understanding what their daily lives are like, but also establishing good relationships and partnerships with the centres we're working with. It's a long term process that we need to work collaboratively on, and it's about knowing the child.'

Source: https://www.ndiscommission.gov.au/providers/understanding-behaviour-support-and-restrictive-practices-providers

Services and Supports

Current pathways are difficult to navigate and often do not meet the needs of the family. Community services in this space need more training to feel confident in better understanding and supporting children and young people with intellectual disability that present with behaviours of concern (Pillai et al, 2022).

Teams can include:

- Schools
- Child and Adolescent Mental Health Services
- Community-based services
- NDIS – Behaviour Support
- Allied Health
- Informal supports (family, friends, community)

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Aggression and self-harm

Mental Health and Behaviours of Concern

The relationship between behaviours of concern and mental health conditions is complex.

In the context of young people with intellectual disability, behaviors and manifestations of mental illness can easily be misinterpreted.

Behaviours of concern and mental ill health are both common in younger people with intellectual disability.

They may co-exist and interact. We need to have a clear understanding of how they relate to one another.

Mental Health and Behaviours of Concern

Behaviours of concern may be present or absent at baseline in a young person with intellectual disability

In the context of new onset or relapse of mental illness, behaviors can appear for the first time or be worsened.

If they are associated with a mental illness they can have various relationships to the illness:

- a core feature of mental illness

  (e.g., aggression and self-injury may be a feature of depression)
- as an atypical feature of a mental illness

  (e.g., repetitive skin picking may be part of an underlying obsessive-compulsive disorder)
- a non-specific manifestation in the context of distress/activation associated with a mental illness.

Mental Health and Behaviours of Concern

In the context of behaviours of concern, a mental health condition may be overlooked.

This is called ‘diagnostic overshadowing’

This is more likely in a person with additional communication needs, severe disability or when clinicians are inexperienced or don’t know all the information about the person.

Less commonly, behaviours of concern can be mistaken for a mental health condition.

Mental Health and Behaviours of Concern

The relationship between behaviours of concern and mental health conditions is under-researched, with insufficient evidence to make a definitive statement about whether any particular behaviours relate to particular conditions.[1]

However, behavioural difficulties in people with intellectual disability have been associated with:

- depression [2]
- anxiety [3]
- psychosis [3]
- affective disorder [4]
- post-traumatic stress disorder [5-7]
- attachment disorder.[8,9]

Aggression

Aggression is a behaviour of concern which can take many forms:

- verbal aggression
- physical aggression
- self-harm or injury
- other destructive or disturbing behaviour

Aggressive behaviour carries the risk of:

- physical and emotional harm to self, family members, carers and community
- disruption of important relationships with family, peers, and important carers
- repeated aggression creates an increasing risk for isolation and restriction

Self-Injurious Behaviour (SIB)

Severe, recurrent and chronic form of behaviour where a person causes physical injury to one's own body. [10]

Young people engaging in SIB may not be intending to cause physical injury to themselves.

Types of SIB include:

- head banging or hitting
- biting
- skin picking, pinching, or scratching
- hair pulling
- eye gouging

It is common for people with intellectual disability who engage in SIB to engage in multiple forms of SIB.

Self-Injurious Behaviour (SIB)

Risk factors:

- Severe/profound intellectual disability, co-occurring autism, and severity of communication difficulties.[11]
- Evidence of a relationship between age and aggression and/or SIB - more common in childhood, adolescence and young adulthood, before decreasing later in adulthood.[12]

Impact:

- SIB is a significant barrier to quality of life.
- Risk to self and others.
- For families and carers, SIB disrupts family life, lowers well-being, and creates chronic stress at multiple levels of the family system.[13,14]

Behavioural Risk Assessment

Behavioral assessment generally centers on observation and measurement to develop a hypothesis of behavioural function to guide treatment planning (Lloyd & Kennedy, 2014).

Assessment of function does not necessarily include an assessment of risk to self or others resulting from behaviours of concern.

In some instances, it may be important to conduct a risk assessment prior to functional assessment.

Behavioural Risk Assessment

Behavioural risk assessment focuses on the form of aggression, impact on safety and predicting occurrence in various contexts.

It evaluates factors such as

- context for the behaviours
- the intensity and frequency of aggression
- the potential targets and location of occurrences
- unusual forms of aggression (topography)
- the presence of any complicating factors or features that increase risk.

Understanding these variables can help to develop more options for risk prevention or mitigation than functional assessment alone.

Behavioural Risk Assessment

Three-phase process:

- record review
  - prior aggression
- interview with carers and young person
  - identify range of aggressive behaviours (present and past)
  - open-ended questions, checklist of high-risk behaviours
  - rating scales (e.g., Behaviour Problems Inventory) to estimate frequency and intensity of behaviours
  - identify if objects are used as weapons and if access to these can be limited
- direct observation

Service Protocols and Specialist Support

Where possible, locate local protocols and policies in advance and familiarize yourself with these. This can help to reduce ad hoc approaches.

How to proceed after a risk assessment:

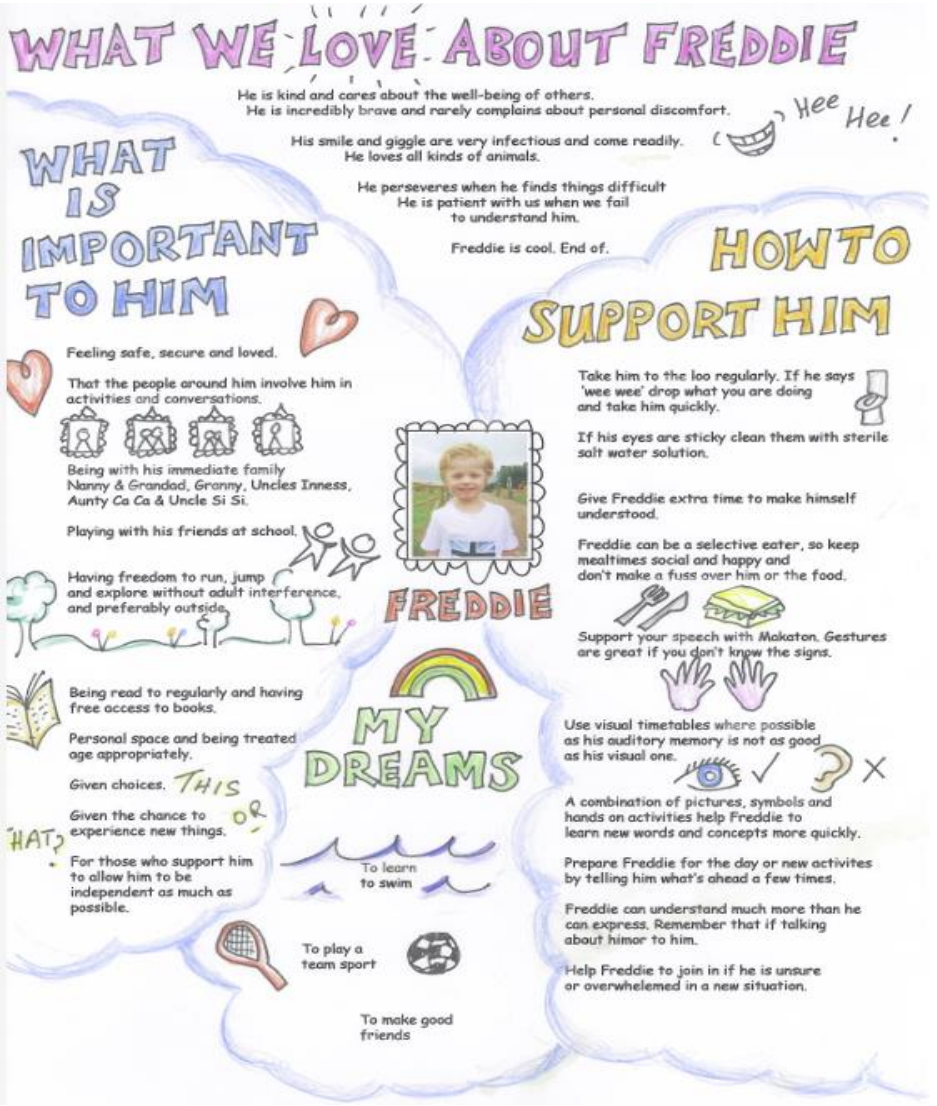
- identify local intellectual disability health/mental health specialists in your service that may be able to provide advice
- identify appropriate behavioural support services and assess access to funding/referrals
- consider implementing an interim emergency plan whilst mobilising resources

De-escalation and harm minimisation

Aim for a Pro-active Approach

The more we know ahead of time the better we can support a child with intellectual disability.

- Provide and take the extra time.
- Planning and predictability.
- Unique one page profile.
- What might trigger a behaviour? Can it be changed or avoided?
- Visual supports and easy read formats.
- Time, patience and compassion.



Source: Marianne Selby-Boothroyd

Responding

- Stay calm
- Co-regulation
- Maintain a safe and supportive rapport
- Attune to their level of communication and physical space needs
- Self-reflection
- Respect
- Trust
- Equality and family expertise

Photo by Artem Beliaikin on Unsplash

Response Planning

LEVEL	What you might see:	Regulation needs/level	What you can do
1 BASELINE	Calm Happy Engaging with activities Interacting socially	Self-regulating	
2 LOW LEVEL AGITATION/ AROUSAL	Louder voice Verbal resistance Complaining Irritability Pacing Self-talk	Co-regulation Prompt self-regulation Support and re-direction	
3 ESCALATED/ AROUSED	Shouting Swearing and threats Refusal to comply (verbal and physical) Hitting out	Co-regulation Deescalate Need for safety	
4 HIGHLY ESCALATED/ OVER AROUSED	Physically lashing out & Swearing/verbally abusive Screaming	Deescalate Prioritise safety	
5 SUSTAINED ESCALATION/ OVERAROUSAL	Refusing medication Continued heightened arousal – fight / flight	Prioritise safety	
6 RECOVERY	Quiet / withdrawn Crying Tired	Co-regulation Gentle support and comfort Safe proximity	

What helps

- Positive feedback – talk about interest areas
- Quiet location
- Sit down, slow pace
- Minimise distractions
- Stay calm
- Limit number of people talking
- Who are they calmest with?
- Safe boundaries
- Listen and validate

Example: Behaviour management guide from a Children's Hospital.

NDIS example: Response strategies mapped against an escalation cycle

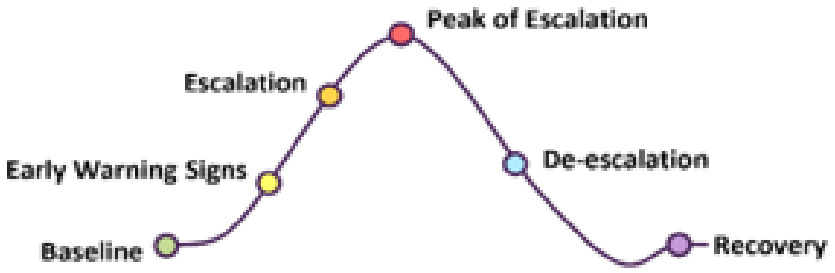


Photo by Dustin Belt on Unsplash

What this looks like	What to do
Baseline • Describe what this looks / sounds like.	• Refer to the proactive strategies section.
Early Warning Signs • Describe what this looks / sounds like.	• Insert response strategies here to help people to respond as quickly as possible to any early warning signs.
Escalation • Describe what this looks / sounds like.	• Insert response strategies here to help people to respond de-escalate the situation.
Peak of Escalation • Describe what this looks / sounds like.	• Insert response strategies here to help keep people safe and minimise the risk of harm.
De-escalation • Describe what this looks / sounds like.	• Insert response strategies here to support de-escalation and calm the situation.
Recovery • Describe what this looks / sounds like.	• Insert strategies and supports here that are needed following the incident. E.g., debriefing, relational repair and support to re-engage in routine activities.

Adapting Our Approach

- Rapport and interests
- Communication:
  visuals, gestures, nod, key words, scripts
- Structure and predictability
- Maintain focus
- Provide a meaningful and concrete passage of time
- Energy required of the child
- Choice and control

Photo by Tom Larsen on Unsplash

Prohibited Practices

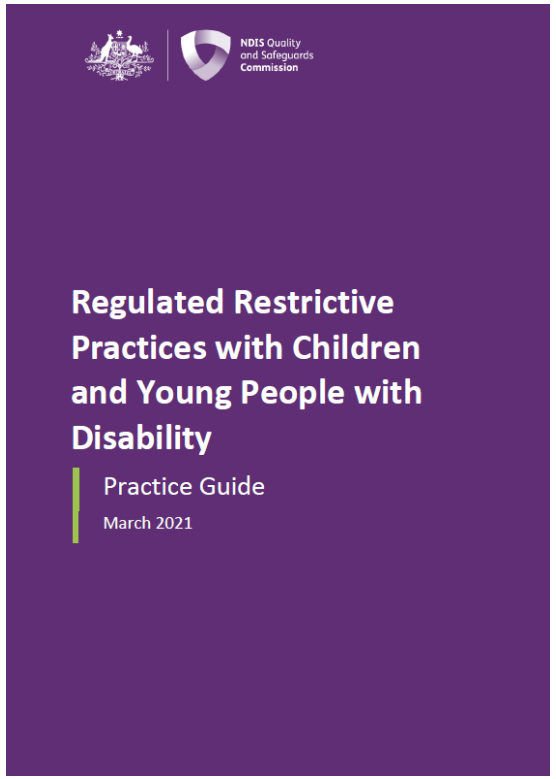
- Aversive practices
- Overcorrection
- Denial of key needs
- Degradation or vilification
- Deny access to culture
- Response cost

Photo by Nick Fewings on Unsplash

Restrictive Practices

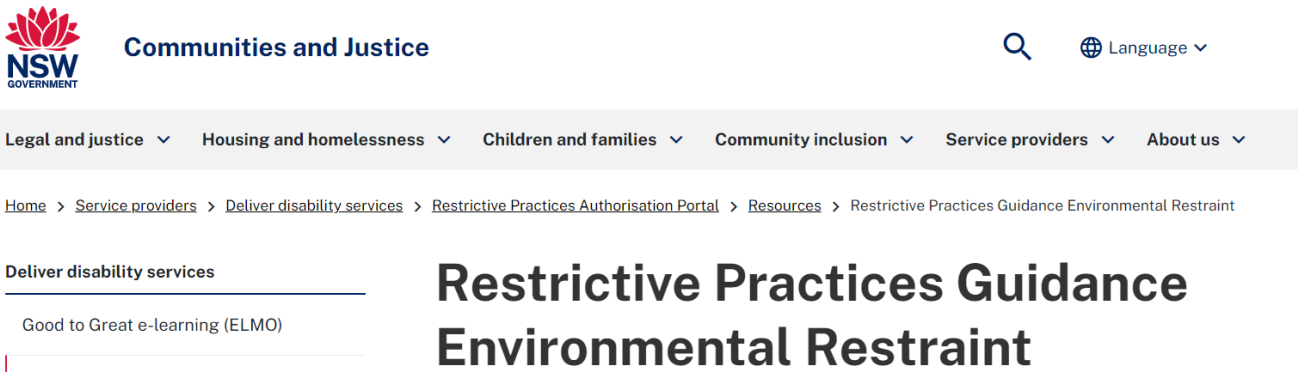
‘Any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability.’
NDIS Quality and Safeguards Commission, 2020

‘Restrictive practices should be used only in limited circumstances as a last resort and not as a first response to behaviours of concern, or as a substitute for adequate supervision. We are working towards the reduction and elimination of the use of restrictive practices.’ NSW DCJ



Restrictive Practices Include:

- Seclusion
- Physical Restraint
- Mechanical Restraint
- Chemical Restraint
- Environmental Restraint



'Restrictive practices are highly distressing for the person who is being controlled or sedated. People who have experienced the use of force or coercion during past trauma can be re-traumatised when a worker uses restrictive practices.'

- A person with lived experience of a MH

Source: NSW Health https://www.health.nsw.gov.au/mentalhealth/psychosocial/principles/Pages/restrictive.aspx

Photo by Susan Wilkinson on Unsplas

Resources

- UNSW 3DN – Disability Professionals E-learning
- NSW Department of Education Fact Sheet
- Education Rights – Behaviours of Concern and PBS
- Victorian Department of Health and Human Services- PBS Assessment tools and templates
- NDIS – PBS and Restrictive Practices
- NSW Health: Managing Anger
- Tas Health: De-escalation Techniques
- https://www.nds.org.au/resources/all-resources/zero-tolerance
- National Disability Service (NDS) – Behaviour Support Training Videos

Pharmacology

Pharmacology and Behaviours of Concern

- Use of psychotropic medication to manage behaviours of concern is widespread, even in the absence of a mental health condition.
- Evidence for the effectiveness and safety of medications used in this context is limited and of poor quality.
- Medications may reduce behaviours in the short-term, but risk of significant side-effects
  - metabolic syndrome, movement disorders, cardiovascular side-effects etc.
  - can also exacerbate existing behaviours or precipitate new behaviours
- Non-pharmacological interventions are the first-choice treatment.

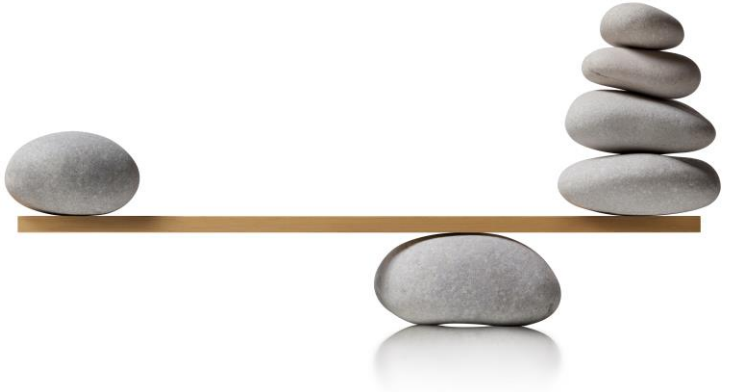
Pharmacotherapy Balancing Act

Inappropriate prescription of psychotropic medications is common.

- Excess use, dose and poorly targeted especially in behaviours of concern
- Prolonged treatment
- Poor monitoring for side effects
- Polypharmacy (concurrent use of two or more psychotropic medications)

Psychotropic polypharmacy is significantly higher in young people with intellectual disability and is associated with:

- an increase of adverse effects from medications and medication-related hospitalisations
- a decrease of benefit from individual medication
- poorer health outcomes.



Chemical Restraint

Chemical restraint is the use of medication for the primary purpose of influencing a person's behaviour and is considered to be a restrictive practice.

- It does not include the use of medication prescribed by a medical practitioner for the treatment of, or to enable treatment of, a diagnosed psychiatric disorder, physical illness or medical condition.
- If sedation is required to contain a dangerous situation, it should only be used as a temporary measure and should not become part of routine behavioural management.

When is it Appropriate to Prescribe?

- If the behaviour poses a substantial risk to the young person or others or is significantly reducing the person's quality of life, and no specific cause or contributor to the behaviour of concern can be identified or managed.

  - When nonpharmacological strategies have been implemented and proven to be ineffective.
  - High risk of immediate harm (after attempting verbal de-escalation and making environmental changes).
  - To treat underlying mental health conditions e.g., depression, anxiety and schizophrenia.

TGA Approved Medications

Antipsychotics may reduce arousal and anxiety contributing to a behaviour of concern in young autistic people.

Risperidone

- Some evidence for the effectiveness of risperidone in addressing behaviours of concern in children with autism, including those with intellectual disability.
- Approved for children over 5 years old

Aripiprazole

- Similar clinical efficacy to risperidone, but less trial data to support its use.
- Approved for young people with autism and behaviours of concern

Chlorpromazine

- Approved for children with behaviour of concern and developmental disability [15,16]

However, National Institute for Health and Care Excellence (NICE) guidelines state that these medications should not be used to treat core symptoms of autism.

Treating Comorbid Conditions

Treating comorbid physical or mental health conditions in young people with intellectual disability is essential for managing behaviors of concern.

- If a comorbid condition has been identified, this should be treated first to see if it reduces the behaviours of concern.
- Appropriate use of ADHD medication in young people with underlying ADHD has been shown to reduce psychotropic polypharmacy and improve behavioural difficulties.[17]

Assess Before You Prescribe

Assessment of psychiatric symptoms

Home medicines review

Nutrition, diet and physical activity assessment

Assessment of home and work environment

Assessment of comorbidities

Communication assessment

Pharmacological history

Psychological and behavioral review

Sensory and functional profiles

Full medical history and review

Beginning Treatment

Establish the person's baseline before developing a treatment plan

Start low and go slow

New medication or medication changes should be treated as a time-limited trial with reviews at planned intervals (e.g., at 3 and 6 weeks)

Treatment should be managed by a clinician with expertise in using psychotropic drugs in children

Prescribing and monitoring principles

Take into account medical comorbidities

Develop a plan to monitor efficacy and side effects

Prescribe medication that does not require blood tests to monitor safety

Monitor cardiometabolic risk

Start with the minimum effective dose and treatment length

Minimise polypharmacy

Monitoring Treatment

Collect objective data

- Clear targets for prescribing
- Metabolic side effects monitored via weight charts and blood tests
- Behavioural changes monitored via sleep and behavioural charts
- Other specific data based on the risk profiles of the medication and the young person

Collect subjective data

- Young person and carer reports on history, observations and experiences
- Ask about side effects

Home Medicines Review

Provided by a credentialed community pharmacist upon referral from a doctor

Pharmacist will:

- ensure the most beneficial medication regimen is in place
- assess that medicines are taken correctly and that they are effective
- check for potential medication interactions and side effects

Subsidised by Medicare for eligible patients once every 24 months

Reviews can be scheduled more frequently in some situations

Guidelines & Resources

The Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard (Australian Commission on Safety and Quality in Health Care) provides guidance to clinicians, healthcare services and consumers on the safe and appropriate use of psychotropic medicines.

The Medicine Cabinet from the Children's Hospital at Westmead School-Link has articles about prescribing and articles on different kinds of medication.

UNSW 3DN has a series of podcasts on responsible psychotropic prescribing for adults and young people with intellectual disability.

The Council for Intellectual Disability has a template to assist prescribers in creating an Easy Read Medicine Letter that explains medicine information to people with intellectual disability and their supporters.

Careful monitoring of cardiometabolic risk is advisable. Resources to assist practice in this area are available on 3DN's Positive Cardiometabolic Health For People With Intellectual Disability webpage.

Questions

Thank You

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