

# NON-RESTRICTIVE PRACTICES FOR PAEDIATRIC INPATIENTS WITH CO- MORBID INTELLECTUAL DISABILITY AND/OR AUTISM SPECTRUM DISORDER

## PRACTICE GUIDELINE <sup>®</sup>

### DOCUMENT SUMMARY/KEY POINTS

- Inclusive care for all children and young people with Intellectual disability and/or autism is the responsibility for all staff working within the network to provide patient centred care and provide a safe environment (Trauma Informed Care)
- NSW Health Child and Adolescent Mental Health services are committed to the Creating Positive Cultures of Care initiative, whose aims include the reduction of seclusion and restraint practices in inpatient units. The use of seclusion and restraint with patients should only be implemented as a last resort, where the patient poses danger to either themselves or others.
- Individuals with mental health and *comorbid intellectual disability and/or autism spectrum disorder* can pose a particular risk of escalated behaviours, due to vulnerabilities such as poorly developed communication skills, social relating and emotion regulation deficits, intellectual handicap, limited problem-solving skills, and sensory sensitivities.
- Proactive management for inpatients with these developmental disabilities is therefore essential, to ensure their rights to non-coercive, least-restrictive inpatient care are promoted, upheld, and protected.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

<b>Approved by:</b>	SCHN Policy, Procedure and Guideline Committee	
<b>Date Effective:</b>	1 <sup>st</sup> November 2023	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Clinical Nurse Consultant	<b>Area/Dept:</b> Psychological Medicine CHW

## CHANGE SUMMARY

- Updated with relevant texts
- Updated to current evidence based practice
- Updated with video links to resource material for further comprehensive explanation.

## READ ACKNOWLEDGEMENT

- This policy is applicable for all staff in the SCHN network. All clinical staff currently (or anticipated to be) working with an inpatient young person with intellectual disability and/or autism spectrum disorder are to read and acknowledge they understand the contents of this document.
- All other clinical staff are to be aware of this document.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

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## Purpose and Scope

This document had been developed to support staff working in SCHN mental health units. However the definitions, strategies and philosophy of this guideline is applicable in all health care settings. Staff working outside mental health should refer to additional documents:

### **Local SCHN Guideline:**

- Pharmacological Strategies for Children with Developmental Disability During Investigations/ Procedures ([2019-121](#))

### **NSW Health Documents:**

- NSW Health, Service Framework to Improve the Health Care of People with Intellectual Disability, NSW Health 2012:  
<https://www.health.nsw.gov.au/disability/Publications/health-care-of-people-with-ID.pdf>
- Responding to Needs of People with Disability during Hospitalisation ([PD2017 001](#))
- Admission to Discharge Care Coordination ([PD2022 012](#))

### **Learning Resources:**

- Intellectual disability mental health e-Learning from the Department of Developmental Disability Neuropsychiatry (3DN): <http://www.idhealtheducation.edu.au/>
- Paediatric Improvement Collaborative Clinical Practice Guideline: [Autism and developmental disability – Management of distress/agitation](#).
- ACI Intellectual Disability Network site Non restrictive care for MH patients with co-morbid ID and ASD <https://aci.health.nsw.gov.au/networks/intellectual-disability>
- The Children's Hospital at Westmead School Link:  
<http://www.schoolink.chw.edu.au/publications/>
- The Children's Hospital at Westmead Child Development Services:  
<https://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/developmental-delay-and-intellectual-disability/chw>

This document provides guidelines for facilitating least-restrictive care for inpatient children and young people who have comorbid intellectual disability and/or autism spectrum disorder.

It has been developed to support implementation of NSW Health Policy Directive ([PD2020 004](#)), *Seclusion and Restraint in NSW Health Settings*. It should be considered in the context of this and other NSW Health policies and applied in conjunction with existing practice guidelines that have been developed for the general population (without developmental disabilities).

For SCHN information refer to *Seclusion and Restraint – Mental Health Facilities Practice Guideline* ([2017 016](#)).

For further information and guidance specific to people with an intellectual disability, refer to the [Intellectual Disability Education \(by 3DN\) eLearning](#) site and the [Intellectual Disability Mental Health Core Competency Framework](#), a manual for mental health professionals and accompanying toolkit auspiced by the Department of Developmental Disability Neuropsychiatry, UNSW Australia.

## Policy and Rationale

Child and adolescent mental health services are committed to the reduction of the use of seclusion and restraint within the hospital. This policy reflects best practice in the management of the inpatient with Intellectual disability and autism spectrum disorder to be cared for in an environment that is safe, respectful, and minimally restrictive.

This policy will help staff identify escalation behaviours and put in place reasonable adjustments to care to provide adaptive care pathways.

The term intellectual disability (ID) is used to describe people who have a general delay or deficit in their intellectual functioning and adaptive skills, with onset during the developmental period. To meet formal criteria for intellectual disability, the diagnosis must be determined by clinical evaluation and standardised intelligence testing (typically at or below the bottom 2% of the population). The individual's adaptive functioning also needs to be considered – i.e., their conceptual (e.g., thinking, problem solving, memory, academic skills etc), social and practical skills.

Individuals with ID have difficulties with cognitive tasks and daily living skills, including understanding abstract concepts, performing complex tasks, and with learning and evaluating new information as quickly or effectively as other people their age. Intellectual disability can be classified as mild, moderate, severe, or profound, depending on the level of impairment, and the extent of the functional support needs of the individual.

A mild level of intellectual disability may be quite subtle to detect, especially on a first or brief meeting. Skills in areas such as personal care, conversational language, and routine social activities may appear fine. However, the individual is likely to have difficulty with abstract reasoning, problem solving, and planning skills. They may be poor at detecting risk, or generalizing skills from one situation to another. Social immaturity or naivety is common.

An individual with a moderate level of intellectual disability presents with more marked difficulties, for example, may need ongoing assistance with elements of personal care, may have only very elementary language skills, and generally requires persistent and repetitive teaching to master basic skills. Socially, capacity to form strong attachments with family and friends is evident, but the quality of these relationships may be less nuanced, and social judgment and decision-making skills are limited.

Individuals with severe and profound levels of intellectual disability have limited capacity to acquire conceptual skills and tend to experience their world in a very concrete, function-oriented way. Spoken language, if present at all, comprises only single words or short phrases, and comprehension is similarly limited. Language use is predominantly action- or object-oriented. The individual requires substantial support from carers to achieve most activities of daily living (e.g., dressing, bathing, toileting, feeding). Maladaptive behaviours (such as aggression and self-injury) are present in a significant minority.

Individuals with an intellectual disability are diagnosed according to the DSM-V. Deficits in functioning can be described across various domains, for example:

Level of ID	IQ	Equivalent Mental Age as Adult	Functioning
<b>Mild</b>	50-69	9-12 yrs	<ul style="list-style-type: none"> <li>• Skills acquired late</li> <li>• Sufficient speech</li> <li>• Independent self care at home</li> <li>• Struggling with academic work – reading, math</li> <li>• Unskilled or semi-skilled manual labour</li> <li>• Can live independently with minimal support</li> </ul>
<b>Moderate</b>	35-49	6-9 yrs	Slow acquisition of language, but usually acquire adequate functional speech. Adults require some degree of support in community – e.g. group homes. <b>May be able to read but with difficulties.</b>
<b>Severe</b>	20-34	3-6 yrs	Daily assistance needed with self-care and safety supervision.
<b>Profound</b>	<20	<3 yrs	Continuous care needed, severe limitation in self-care, continence, communication and mobility.

- <https://mypositiveparenting.org/wp-content/uploads/2017/11/parenting-a-child-with-intellectual-disability-education-and-training.jpg>

Individuals with intellectual disability may experience mental health conditions. For more information, this video (<https://www.youtube.com/watch?v=NUZjeJ3gstc>) provides an overview of mental health conditions in the context of intellectual disabilities, and is aimed at achieving these 3 outcomes:

- To understand the relationship between intellectual disability and serious mental illness.
- To understand the principles for the assessment of people with intellectual disability and mental health dual diagnoses.
- To understand the options for access to care in intellectual disability neuropsychiatry.

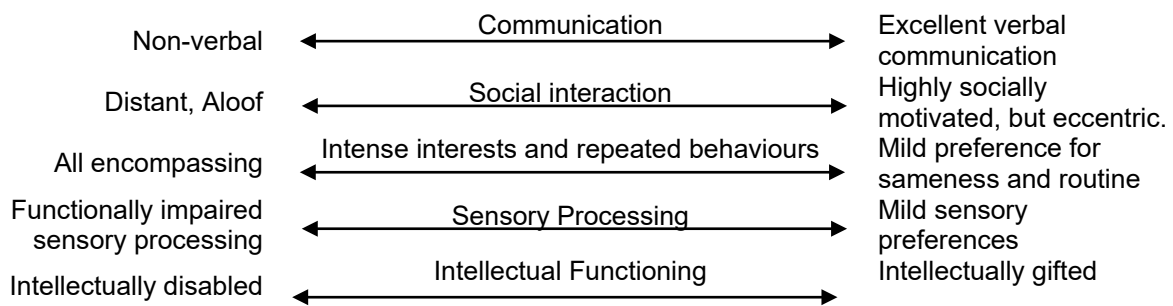


## Autism Spectrum Disorder

Autism Spectrum Disorders (ASDs) are lifelong disorders that first begin in childhood and affect the person's day to day life. They are characterised by difficulties with social interaction and communication, as well as strong and intense interests in specific topics, and repetitive behaviour. As the name suggests, individuals with ASD fall on a continuum from mild to severe. The current diagnostic criteria group the previous diagnoses of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

Individuals with ASD have challenges with social relationships including forming and keeping friendships, recognising how other people might be thinking and feeling, and following the unspoken social rules in an interaction. They can insist on following the same routines and thus struggle with change. Sensory sensitivities (e.g., intense dislike of loud environments) can also be present.

Each of these challenges can exist along a continuum for different people. For example:



Autism spectrum disorders is now classified as, level 1,2and 3. This is dependent on the level of support a person is required to be able to function, experienced by the individual because of both their social-communication difficulties, and their restricted and repetitive interests and behaviours.

More information to assist with understanding autism diagnosis:

- Autism Awareness Australia, [Understanding Autism](#).
- Autism Spectrum Australia, [What is Autism?](#).
- *Video: [Amazing Things Happen](#)* – introduction to autism for young non-autistic audiences, aiming to raise awareness, understanding and tolerance in future generations.

## General Principles

### Communication

A patient's ability to speak and use language (i.e., expressive language) may be vastly different from their ability to understand what others are saying (i.e., receptive language). In cases where their expressive is better than their receptive language, patients can seem more capable than they are, and this can lead to expectations of their behaviour and self-regulation that are mismatched for their developmental stage. In cases where receptive is better than expressive language, others may assume that the patient is less capable than

he/she is. This can lead to frustration as they are 'talked down to' or being excluded from developmentally appropriate activities, as others underestimate their ability to participate.

It is important to clarify the forms of communication used by the individual, including visuals, Key Word Sign or specific communication apps. Many individuals with intellectual disability and/or autism use multiple methods of communication and may use a different method for expressive language and receptive understanding. The individual's preference for communication should be used wherever possible. This may involve the creation of additional resources, e.g., visuals, to support new routines or procedures.

Non-verbal communication may also be significantly affected in those with intellectual disability and/or autism. This can range from a lack of eye contact, gesture, facial expression, and body language, through to difficulties integrating these. They may also have significant impairments in interpreting the non-verbal communication of others.

- For more information, see [Communication: Autistic Children](#) page on the [raisingchildren.net.au](http://raisingchildren.net.au) website.

### **Social and Emotional Development**

A person with intellectual disability may present as appearing to be socially immature, with skills more consistent with that of a younger child. They can also be very concrete in their use of language, and unable to understand sarcasm and metaphor. Social cues from others can also be missed or misread, leading to difficulties in accurately judging or managing a situation where asked to do something beyond their capacity.

The patient may have great difficulty with regulating their emotions and controlling their behaviour. This may be more evident during changes to routine, unexpected events or poor communication.

### **Sensory issues**

The patient may have difficulty processing and regulating information from various sensory systems i.e., auditory, visual, touch, movement, taste, smell, vestibular, proprioceptive and interoceptive.

Some patients may be over-responsive to certain sensory experiences, and this can lead to avoidance or challenging behaviours. For example, sensitivity to loud noises, fussy eating, and distress doing self-care tasks like attending to their ADL's (Activities of Daily Living).

Some patients may be under-responsive to certain sensory experiences. That is, they have decreased awareness of certain sensations, which can lead them to seek out experiences to increase their sensory input. For example, humming and making sounds, putting objects in their mouth and other orifices, touching various surfaces or objects, or turning devices up to full volume.

Difficulty processing and regulating sensory information can impact on learning and play skills, body awareness, regulation of emotions and behaviour, and ability to participate in daily tasks and activities.

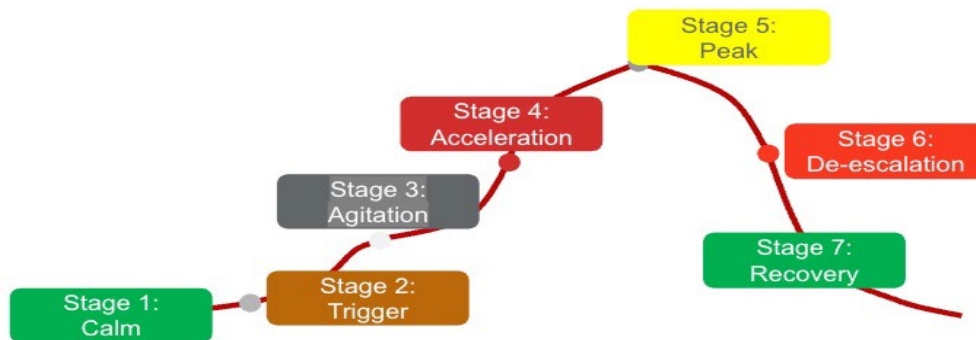
### **Behaviour**

Maladaptive behaviours are present in a significant minority of individuals with ID and/or ASD. This can include self-injury (e.g., head banging), aggression directed at others with or without intent (e.g., biting, hitting, kicking, yelling etc), destruction of property, tantrums/melt downs, and absconding.



In part due to the communication impairments common to both ID and ASD, individuals may commonly use behaviour to express a range of issues including anxiety, frustration, confusion, fear, distress, tiredness, overload of information, overload of stimulation, boredom and pain. Behaviour can also be a means through which to express likes and dislikes, to communicate wants or needs, or to gain social attention. Establishing the communicative function of a behaviour is a critical step in the process of redirecting it.

Understanding of the [Escalation curve](#) is important in planning inpatient care:



Understanding the behaviours of the child or young person with ID and where they are in the escalation curve assists us to put into place the reasonable adjustments requirement to keep them calm and safe.

## Common learning characteristics for individuals with ASDs

Every experience of ASD is different. Patients presenting with high-functioning or Level 1 ASD will generally present quite differently to a patient with Level 3 ASD. The following learning styles should be taken into consideration during assessment but must be graded to match the individuals' strengths and weaknesses.

- **Visual Learning Style**

Individuals with autism often have stronger visual-spatial skills compared to other cognitive areas, and thus prefer visually presented material. It can be helpful to use visual supports (e.g., diagrams) in discussion, particularly when new information is being presented, and to use methods of visual communication where possible.

- **Concrete and literal thinking**

Children with autism tend to be very concrete in their style of thinking. This can include literal interpretations of language, difficulty understanding idioms and metaphors, and difficulties grasping that two words can mean the same thing (e.g., eggplant and aubergine), or that one word can have multiple meanings. These individuals will often need explicit explanation of these concepts.

- **Creative and Unconventional World View**

Due to their often-idiosyncratic perspectives people with autism often think of ideas that others do not. This results in them being often very creative thinkers with ideas that are outside the box.

- **Passionate About Their Interests**

Intense and specific interests are part of the core features of autism however this can also be viewed as a strength. Children with ASD can derive great pleasure and

satisfaction from their interests. Using these interests can be a way to engage and motivate these children when under unfamiliar and stressful circumstance of a hospital admission.

- **Rule-governed and rote-based learning**

Children with ASD tend to have a strength in rote memory skills, though may not always attend to or process the meaning of what they remember. They can also learn information as 'chunks' (e.g., sections of dialogue from a film). This characteristic can also present in individuals in terms of their preference for routine and familiarity.

- **Weak Central Coherence**

The concept of central coherence is 'grasping the whole' or 'having a sense of the bigger picture'. This is often difficult for individuals with ASD. They may pay close attention to the details or overly focus on irrelevant or minor details, rather than seeing how they fit together and recognising what is most relevant for them to focus on.

- **Poor executive functioning**

Executive functioning refers to skills such as planning and organisational abilities, ability to hold and manipulate information in memory, inhibition and impulse control, attention, and flexibility and problem solving. Impairments in executive functioning can be observed in people with ASD in characteristics such as difficulties in shifting attention from a current focus to something different, difficulties in sustaining attention when there are external distractors, difficulties in coping with change or unpredictability, and seeming to 'respond without thinking'.

- **Responsiveness to Structure**

Children of autism like routine and structure, as it means that it is more predictable and calmer. As a result, putting together a timetable or a set plan for treatment can increase the likelihood of these children responding well to their admission.

## Management Strategies

### General Management Principles

- Refer to the Paediatric Improvement Collaborative Clinical Practice Guideline, [Autism and Developmental Disability – Management of distress/agitation](#), housed on RCH Melbourne website.

### Reasonable adaptations that need to be considered when caring for a young person with Neurodevelopmental difficulties.

When meeting a patient with an intellectual disability and/or Autism, it is important that we get to know the patient and their families, the patient's likes and dislikes, and what supports they may need to complete routine activities of daily living such as personal hygiene, toileting, dressing, and feeding.

When meeting a patient with Intellectual disability and/or Autism, as when we meet any new person, we need to observe their behaviours and mannerisms to assist us to better understand how they function in the current situation.

The patient may demonstrate less awareness of, or capacity to comply with, domestic and community routines, such as with taking care of their belongings, assisting with chores, and observing organisational protocols. They may have specific strategies that they find helpful, and that can be replicated in inpatient settings.

The patient may demonstrate a naivety or reduced appreciation of potential environmental dangers, such as when around kitchen facilities, with other patients, or in the dispensing of medications.

A patient with an intellectual disability and/or Autism may need additional time to process a change in environment (such as an unexpected admission). This may result in increased behaviours and require additional supports.

We can have a chat with the Child or young person and their family to learn more about them. Are they comfortable being near us? How do they communicate with us, and is there a topic that makes them feel more comfortable? Maybe the person would prefer that we do an activity together at which there will be less pressure to talk. Routine and predictability are likely to make activities easier to understand and more comfortable than impulsive, random actions and activities. Perhaps a visual indication of the steps of an activity or order of daily activities will provide the person with a clear view of what to expect – which can reduce anxiety in situations presented.

Derbyshire Healthcare UK encapsulates examples of reasonable adjustments into the following points:

1. Improving appointments
2. Good Environment
3. Understanding behavior
4. Telling people what you are doing
5. Information from people
6. Helping people understand
7. Keeping language simple
8. The support people need



**Figure 4.** Examples of reasonable adjustments in health care for a person with intellectual disability - health staff level<sup>5</sup>.

In providing reasonable adjustments to a person with intellectual disability, one of the critical factors lies in the understanding of the person's care needs and their communication level and style. Many services have developed "hospital passports" or "all about me"/"personal disability plan" to assist with the planning and use of specific communication strategies when a person with intellectual disability is admitted to hospital. These resources contain information about the person's health issues as well as how they communicate, what type and level of care they require, their early warning signs of distress and how others can support them to de-escalate when early distress is identified. If the patient doesn't yet have a similar plan compiled, it may be helpful to complete one with the family and ask them to bring it with them whenever the patient attends a health care setting. With appropriate consent, it may also be helpful to seek advice or support from private treating teams (such as Occupational Therapy, Psychology or Behaviour Support Therapy).

- The **Hospital Passport** can be downloaded from here:  
[https://www.schn.health.nsw.gov.au/files/attachments/hospital\\_passport\\_form.docx](https://www.schn.health.nsw.gov.au/files/attachments/hospital_passport_form.docx)
- **Factsheets** to assist with understanding the using the health passport:
  - [https://www.schn.health.nsw.gov.au/files/attachments/about\\_me\\_profile\\_fact\\_sheet\\_for\\_families.doc](https://www.schn.health.nsw.gov.au/files/attachments/about_me_profile_fact_sheet_for_families.doc)
  - [https://www.schn.health.nsw.gov.au/files/attachments/about\\_me\\_profile\\_fact\\_sheet\\_for\\_health\\_professionals.doc](https://www.schn.health.nsw.gov.au/files/attachments/about_me_profile_fact_sheet_for_health_professionals.doc)

### ***The Top 5 Resources***

[The Top 5](#) is an alternative resource to the hospital passport that provides a quick way to identify ways to communicate and manage a person with intellectual disability and/or ASD in distress.

Top 5 is a written tool that is used to assist staff to better understand the needs of a child in their care. This is discussed in conjunction with the parent/carer to understand the "must haves", their likes/dislikes, their fears and routines. It also assists in understanding how to soothe and comfort when they are frightened, anxious or upset.

This assist staff to try and keep the child in a calm state and to recognize what might "set them off". This information helps to develop a quick understanding of the child's behaviours and how they communicate.

## **Teamwork and collaboration**

Emotional and behavioural disturbance in young people with intellectual disability and/or ASD needs to be assessed from a multidisciplinary perspective. Each discipline can contribute perspectives to the disturbance and to approaches to skill building to enable improvement. For example, consider input from a speech therapist to review communication capacity or an occupational therapist for review of sensory processing issues. Functional impairment is often due as much to emotional and behavioural disturbance as it is to underlying intellectual disability. All cases should be considered from both a behavioural (challenging behaviour) as well as a psychiatric perspective. Often challenging behaviours are associated with significant psychiatric disorders (often more than one) and therefore need multimodal approaches to intervention.

Family members, carers, and other service providers can provide invaluable information to support a patient with ID/ASD during an inpatient admission. This can include information about; their likes, dislikes and preferences; their communication skills and strengths; common antecedents for challenging behaviours; strategies for self-soothing. Family and service providers are also well placed to give feedback about how typical or not particular behaviour or responses are, and how generalizable any inpatient strategies will be when applied to the patient's environment outside the hospital.

## Positive Behaviour Support - Creating a Behaviour Management Plan

Positive behaviour support involves proactive management of a patient's environment to minimize the risk of challenging behaviours and maximize patient engagement with the appropriate activities of the ward. This includes having a good understanding of common antecedents and triggers of a patient's challenging behaviours, and use of a range of strategies to pre-empt recurrence of these triggers in other environments.

- **Structured teaching**

This is an approach to supporting individuals with ID and/or ASDs that involves structuring the environment so that this itself acts as a way of enhancing a patient's participation. This is achieved through incorporating structures such as the use of schedules, tasks & work/activity systems, and routines. Examples of incorporating structured teaching into an inpatient environment could include:

- Using visual markers in the environment (e.g. a chair to indicate that the patient needs to sit, a footprint template to show where to stand, colour-coding of materials to show that they 'go' together, use of mats or other floor markings to create visual boundaries for different areas (e.g. the green mat is where you can watch TV, the red mat is where we sit for meals, the lino floor shows where we do painting and craft)
- Using the environment to communicate the duration and/or nature of a task (e.g., keep all the materials required for a particular activity in a labelled box or folder; use of strategies such as templates with empty spaces, or worksheets with drawn lines - to represent visually where a task starts and ends).
- Use of 'natural' environmental cues to help patients identify important elements in their environment to attend to (e.g., a clock face as a visual indicator of when visiting times start or end)

- **Teaching of effective skills**

This involves teaching the 'what to do' as a management approach for reducing the 'what *not* to do'. This is important because for many individuals with ID and/or ASD, they are not aware or attuned to what behaviour is expected or appropriate for a given circumstance. Feedback to stop a behaviour can create a behavioural 'vacuum', because the individual does not know what behaviour they should demonstrate to replace the behaviour they have been asked to stop. Teaching effective skills addresses this issue by equipping patients with ASD with clear and explicit information about what behaviours and skills are appropriate.



- **Establishing the communicative function of behaviour**

This involves establishing what message the patient is trying to convey through their behaviour. It is important to remember that this message can often be unintentional. Once there is a sense of what function a behaviour is serving, this can guide what adjustments or supports can be put in place to enable the patient to communicate their needs in a more appropriate way.

- Positive feedback and encouragement to reinforce desired behaviours.
- What does the patient like –what is reinforcing for them (this will likely be different for different patients, and often different for patients with ASD. Special interests can often be used as motivators/reinforcers (e.g., an interest in trains)
- Use of reward charts –where patients can be allocated points for their participation in activities or cooperation with routines. A small reward (e.g., an inexpensive toy, computer time, time off the ward) to be offered after accrual of an agreed number of points.
- Enable success – ward staff should monitor & ensure that the patient has success with at least parts of their program on a daily basis. Being able to do something successfully helps to build confidence, and boosts their enjoyment in the program, both of which are motivating and aid learning. For patients who are finding the admission more challenging, consider:
  - *Scaffolding* – which involves providing extra prompts until the patient is able to perform a routine task successfully or to engage with an activity appropriately.
  - *Using graded questions/instructions* - which involves ensuring opportunity for all patients (& particularly those who are less capable) to engage appropriately with staff. This may include simplifying questions/instructions as necessary.
  - *Attending to and using 'unintended' contributions as teaching opportunities.* This involves acknowledging and incorporating the comments made by the patient into the program, even if on the face of it they may seem rude or disruptive. For example, John complains that an activity is too difficult and he is not going to take part. Staff could turn this into a teaching example; “*John is showing us one strategy that can be helpful for managing stress –removing ourselves from the stressful situation. What is good about his strategy? What might be not so good? What is another way he might deal with the problem...*” etc.

The Neurodevelopmental Team will create a Behaviour Support Plan for Inpatients based on information collected about the child's communication, sensory needs, likes and dislikes and triggers. This will support the ward staff to help minimise behavioural escalations on the ward. This links to the escalation curve.



## Environmental adjustments

### ***Planned admissions.***

Before a planned admission, in addition to information provided to the patient and their primary carers about the unit, reciprocal information should be sought about the patient, particularly, what accommodations or supports would be helpful in facilitating their hospital stay. Where practicable, existing supports (such as communication systems, reward charts, feelings toolkits etc) from the home/school environments should be adopted (or adapted) into the hospital setting. Full medication reconciliation should be done prior to any planned admission, by the referring team.

### ***Emergency admissions***

In the case of emergency admissions where such preparations have not been possible; basic information should be sought from the primary carer (e.g., about likes/dislikes, common triggers, effective reinforcers). Any existing supports from home/school should be introduced soon after admission. As full a medication history as possible should be compiled, based on information provided by the primary carer, and the patient's medical records.

### ***Resources***

A general resource kit kept permanently on the ward could include materials such as materials for a visual schedule, or to convey ward rules (with common ward activities, depicted at several levels of visual literacy – e.g. in words, in photos, in line drawings), several styles of reusable reward charts, a 'sensory bag', a basic social story about day-to-day life on the ward, and an iPad (or other technological aid device) preloaded with applications that can provide these resources. The kit could also include a 1–2-page form/template for a carer to complete, providing structure and prompts to gather information about interests, preferences, triggers, and strengths.

A safe withdrawal space on the ward for 'down time' should be identified collaboratively with the patient (e.g., for them to withdraw from an environment in response to sensory overload)

### ***Routine and structure***

A key environmental consideration is to provide as much consistency and predictability as is practicable. This is best achieved through a combination of familiar routines, and a clear and effective method for communicating change (be it unexpected disruptions, or regular events such as staff changeovers).

During an admission; the patient's activities for the upcoming time period should be communicated to them at a level that is accessible/meaningful (e.g. for a highly verbal patient, this may be via a written schedule for the whole day; for a less verbal patient this may be via a set of 4 photos showing the morning's sequence of activities, for a non-verbal patient this may be a "first→then" board using real objects (e.g. hairbrush to depict brushing hair, followed by toothbrush and paste to depict tooth brushing; first it is time to brush your hair, then it will be time to brush teeth) etc.

### ***Daily Programming***

Patients with a developmental disability should be given opportunity to participate in all activities (as is, or a customised version thereof) as available to other inpatients on the ward. This would typically require an individualised program that incorporates person-centred versions of these activities into their daily schedule. Examples may include watching

preferred TV programs, playing preferred computer games, participating in outings off the ward, engaging in physical activity (e.g., 'gym' activities, swimming, ball games)

## Communication Strategies

Patients should always be treated with respect, such that communication strategies used should not be too complicated to be understood, and where simple, presented in a way that they are not perceived as patronising.

A patient's communication skills should be gauged as early as possible in the admission process (including in advance, where feasible). When in doubt, adhere to the principle that too simple is rarely a problem, but too complicated almost always will be (e.g., use of a pictogram versus a written word:



vs 'toilet').

Remember that your body language is important because people with an intellectual disability often rely on visual cues. Be prepared to use visual information or to get visual information from people with an intellectual disability. Be specific and direct. Avoid talking using abstracts, acronyms, metaphors or puns.

### **Remember the following principles:**

- Use simple, direct sentences or supplementary visual forms of communication, such as gestures, diagrams, or demonstrations, if indicated.
- Use concrete, specific language. Avoid abstract language and simplistic wording.
- When possible, use words that relate to things you both can see (e.g.: "use the object to help explain what you are going to do").
- Understand communication style. These links assist with understanding communication:

Further resources, see Special Olympics web page on [How to Speak with People with Intellectual Disabilities](#).

### ***Verbal communication***

Verbal information can be simplified by presenting it at a slower speed, with fewer, less complicated words, and in fewer parts (e.g. reduce a multipart instruction to just two-parts, or a two-part instruction to just one etc). Use of jargon, idioms, colloquialisms, and other figures of speech should be avoided.

### ***Visual supports***

Where needed, verbal information should be augmented by visual supports; these can range from use of gestures and written language through to provision of concrete objects, depending on the individual's comprehension level. Visuals can be used in a range of scenarios, including to provide forewarning, to sequence tasks, to show a planned timetable for the day, to prepare for change, to convey 'no', and to label key places.

### ***Social stories***

Social stories can be another vehicle for conveying important social information in a format that is accessible to the patient. Generic social stories about life and routines on the ward can be developed as a general resource, while some patients may need individualised stories developed around their particular needs while inpatients.

## Sensory strategies

Information should be sought from the patient and carers relating to the patients' sensory preferences; what sensorimotor activities they like/dislike and find calming/distressing. Incorporating sensory based approaches into the management strategies can help prevent or quickly resolve escalation. Each patient is individual; has different preferences and will all respond differently to sensory based activities. What one patient may find calming another patient may not, so it is important to gain as much information from patient, carers and observation as possible.

Assess the sensory environment i.e., identify any environmental stressors, in particular lighting, sounds. Modifying the physical environment may help in managing the patient and helping the patient regulate their arousal. For example, providing regular time throughout the day for the patient to have 'down time' in a safe space such as a quiet, darkened room thereby reducing sensory stimulation.

Patients should be given opportunities for sensory breaks regularly throughout the day. For example, this may include spending time in a quiet space alone, playing with sensory box items, or having a movement break.

"Heavy work" sensorimotor activities have the benefits of being able to both increase and decrease arousal. Incorporating activities such as exercise, sport, stretching, weight-baring, pushing/pulling activities into regular daily routine is extremely beneficial.

Other sensory based activities include a sensory bag and trialling the use of weighted modalities such as weighted blankets, lap/ shoulder bags, and vest may be useful for some patients. Use of weighted equipment should be monitored by an Occupational Therapist.

## Medication

There are a number of concerns that are more likely to need consideration in young people with intellectual disability and or ASD. First there is a greater likelihood of medical comorbidity that may need investigation, management, or consideration in prescribing. The developmental profile needs to be considered against which to understand behaviour. Be aware that the presence of one area of disability or developmental delay/disorder raises the risk of another, such a sensory disability (e.g. deafness) or specific learning problems (e.g. Semantic Pragmatic Language Disorder).

There are additional difficulties in diagnosis in young people with intellectual and developmental disabilities. There are additional manuals available to help provide guidance (refs: DM-ID; DC-LD). There are some difficulties in the reliability of diagnoses, as these young people may have difficulty describing their internal mental state (as often applies to younger children). Particularly people with intellectual and developmental disabilities have difficulty describing their level of anxious and depressed moods and other more abstract concepts. These may need careful consideration, from several informants, especially those who know the patient well. Young people with intellectual and developmental disability may well give answers to please the interviewer, or fail to understand the significance of the question (e.g., do you hear voices?). Be aware of their developmental capacity and abilities in theory of mind for understanding a question and influencing the answer they provide. They are more likely to be able to describe changes in their functioning, such as sleep, appetite, losing interest in something or forgetting events or routines. Those with limited capacities of theory of mind may have difficulty distinguishing delusions, hallucinations and flashbacks

from concrete thoughts, stereotypic thoughts and memories, or active pretend and imaginary thinking, dissociation or pseudo hallucinations. Pretend friends and eidetic memory are more common. The diversity of features (e.g., as stereotypic movements) that is characteristic of ASD need to be taken into account when considering psychiatric phenomena.

In those with limitations of cognitive capacity and communication, from both their developmental and their psychiatric disorders, there can be greater difficulty in providing psychological interventions and a greater need to use pharmacological intervention. However, it must be remembered that intellectual disability and abnormality of brain development also increases the risk of medication side effects including serious side effects such as neuroleptic malignant syndrome or a serotonergic syndrome. Greater caution is therefore required in the introduction of medications and the monitoring of side effects. Further there is some suggestion that they may respond more slowly e.g. to a decline of hallucinations with major tranquillisers. The presence of several different psychiatric disorders may nonetheless require an increased rate of using more than one medication, and 'polypharmacy' is required more frequently.

Those with intellectual and developmental disorders may find hospitalisation and an alteration of routines more stressful, and it may take longer for them to accommodate to their new environment and new staff relationships. Active management of their anxiety and distress may need to be anticipated. For example, stereotypic thinking may predispose young people with ASD to a slow crescendo of anxiety and agitation, and a lesser capacity for asking for help.

The principals of medication management may require greater attention to the adage of 'start low and go slow'. However general principals are otherwise similar. Often there is limited literature on the use of medications in this special population, and differences in considering medications, particularly in the presence of side effects from first line medications choices. For example, it may be necessary to consider second- and third-line treatments for ADHD or Anxiety. Mood lability and aggression may benefit from mood stabilisers.

### **Further Resources:**

This link describes additional ways of improving communication with people with disabilities.

- <https://www.nln.org/education/teaching-resources/professional-development-programsteaching-resourcesace-all/ace-d/additional-resources/communicating-with-people-with-disabilities-e030c45c-7836-6c70-9642-ff00005f0421#:~:text=Use%20simple%2C%20direct%20sentences%20or,things%20you%20both%20can%20see>

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