

This Clinical Guideline has been developed by the Centre for Developmental Disability Health in consultation with General Medicine.

Target Population for the Guideline

This Guideline is applicable to all involved in providing healthcare for people with intellectual disability and/or autism spectrum disorders

Target Users of the Guideline

Health professionals providing care to adults with intellectual disability and/or autism spectrum disorders

Background/Rationale

Monash Health is located within a large and diverse community. Health professionals work with many different patient groups, including **people with intellectual disabilities and/or autism spectrum disorders**. There are a number of particular challenges this group of patients face that require understanding and consideration by their health professionals.

- **Previous experiences** in healthcare settings may lead to the patient feeling fearful and distressed. Some people have PTSD from past experiences in healthcare.
- **Cognitive** difficulties may mean the patient has trouble understanding unfamiliar settings, what is happening around them, what will happen to them and what is expected of them.
- **Communication** difficulties may make it difficult for the patient to **understand** what others are saying (**receptive** language) or make themselves **understood** (**expressive** language) to those providing care, or both. The person's behaviour may be their only way of communicating or demonstrating their experience, concerns, confusion or fear.
- **Sensory impairments** may mean the patient may not be able to clearly hear, see or feel what is happening around them.
- **Sensory sensitivities** are very common in people with autism. The person may be highly sensitive to particular light, sound, smell, taste or touch sensations. Some stimuli may be experienced as highly distressing or intolerable, while other sensory experiences may be intensely pleasurable, reassuring or calming. The person's behaviours may reflect their desire or need to actively avoid or seek out various stimuli.
- **Motor** difficulties may mean the patient has less control of their movements, including speech. This may be exacerbated when they are feeling anxious. The ability to speak is independent of cognition or hearing; assumptions should NOT be made that someone who is not able to speak is either deaf or has a cognitive impairment.
- A **lack** of support; **unfamiliar** carers or environment; **change** in circumstances or environment may lead to the patient feeling isolated, frightened and/or confused.
- **Social** difficulties may lead to the patient not fully understanding the social 'rules' of communication and behaviour within the healthcare setting.
- **Service sector interfaces**. People with a disability often require and receive personal and social support through Disability services. When that person becomes ill, they then require

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Health services too. It is important to establish clear communication across this sectoral interface to ensure the person's needs are understood and addressed in a timely and integrated fashion.

Quick Reference Guide

[COVID 19 and People with Disability](#)

[The National Disability Insurance Scheme \(NDIS\) for People with Disability](#)

[Clinical Guideline 1: Understanding behaviour change in people with an intellectual disability or autism spectrum disorder within a healthcare context.](#)

[Clinical Guideline 2: Admission of people with an intellectual disability or autism spectrum disorder to acute health services.](#)

[Clinical Guideline 3: Inpatient care of people with an intellectual disability or autism spectrum disorder in acute health services.](#)

[Clinical Guideline 4: Discharge planning for people with an intellectual disability or autism spectrum disorder.](#)

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COVID 19 and people with disability

- People with disability may be particularly vulnerable to acquiring COVID19, may experience more severe disease, and often experience the secondary consequences of changes associated with the community's pandemic response.
- Many people with disability rely on support and assistance from family members, and/or support workers. They may therefore be exposed to multiple people in a day and social distancing may be difficult or impossible, depending on the assistance they require with personal care.
- Some people with disability live with multiple chronic health conditions. They are at greater risk of severe disease if they contract COVID19.
- Routine health care, disease prevention interventions, and health promotion activities have been delayed, overlooked or missed during the COVID 19 pandemic. These aspects of care should be continued for all community members, including those with disabilities.
- People with cognitive impairments may find hearing about COVID19 from media, staff and family anxiety provoking or frightening. Changes in daily routines required including loss or restriction of usual activities, hand hygiene measures, social distancing, and the use of masks by caregivers may be particularly distressing.
- Some people are not able to tolerate wearing a mask, even after explanation, support and desensitization. Exemptions from the requirement to wear masks have been provided for people with disability who are unable to tolerate them.

<https://www.dhhs.vic.gov.au/face-coverings-covid-19>

Admission to hospital

If COVID testing is for **elective admission** to hospital it is important to check if the person with disability will require a carer/support worker while in hospital; if so, that person will also need to be tested prior to the admission.

Resources

Many useful resources have been developed to support people with disability and those who work with and care for them during the COVID 19 pandemic.

National Resources:

This site provides a range of resources and fact sheets for health professionals, disability workers, and people with disability and their families.

<https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advice-for-people-with-disability>

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National COVID-19 Health Professionals Disability Telephone Advisory Service:

1800 131 330

This service provides specialised advice to health professionals responsible for the medical care of people with disability diagnosed with COVID-19 or experiencing symptoms.

Information and referrals for people with disability and their supporters about coronavirus (COVID-19)

Disability Information Helpline on **1800 643 787**.

<https://www.dss.gov.au/disability-and-carers/information-and-referrals-for-people-with-disability-and-their-supporters-about-coronavirus-covid-19>

Coronavirus (COVID-19) resources for health professionals

<https://www.health.gov.au/resources/collections/coronavirus-covid-19-resources-for-health-professionals-including-aged-care-providers-pathology-providers-and-health-care-managers>

Victorian resources

Information for people with disability and those working with and caring for them.

<https://www.dhhs.vic.gov.au/information-people-disability-coronavirus-disease-covid-19>

Disability Information Helpline on 1800 643 787

Access to information and referrals for people who need help because of coronavirus (COVID-19), including access to counselling

Coronavirus (COVID-19) health professional hotline

Health professionals can call the dedicated hotline – phone [1800 675 398](tel:1800675398), 24 hours a day.

Testing for COVID19:

People with disability can get tested for COVID 19 at the static and drive through clinics available to all Victorians. Details can be found at:

<https://www.dhhs.vic.gov.au/where-get-tested-covid-19>

A **Call-to-Test service** is available to people not able to leave home due to injury, mobility or other eligible reasons. This service provides testing at home by a qualified health clinician. For more information:

<https://protect-au.mimecast.com/s/OnmIC4QZ17U63vPMuBGFZf?domain=dhhs.vic.gov.au>

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Information for people with intellectual disability and or autism and their families:

These resources provide explanations for people with intellectual disability or autism spectrum disorders about COVID 19 and the changes in daily life and routines that have been required by the pandemic.

- **Autism WA** have produced a range of resources to explain COVID 19 and the life changes that have occurred during the pandemic. These resources include Care Boards for hospital care
<https://www.autism.org.au/coronavirus-covid-19-update/>
- **The Association of Children for a Disability** have gathered resources to help children and their families during the COVID 19 pandemic. These include social stories around temperature testing, wearing masks, having a COVID test, caregivers wearing PPE.
<https://www.acd.org.au/covid-19-latest-information/>
- **Department of Education and Training:** talking to your child about coronavirus
<https://www.education.vic.gov.au/parents/Pages/translated-advice.aspx>
- **Council of Intellectual Disability**
<https://cid.org.au/covid-19/#info>

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The National Disability Insurance Scheme (NDIS) for People with Disability

People with a “**permanent and significant**” disability may be eligible for the NDIS and can receive funding for the “**reasonable and necessary**” support they require to optimise “**independence and participation**” in their community.

Information about the NDIS for health professionals:

<https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals>

Information about NDIS funding for Disability-related health supports:

The NDIS does not fund health services – that is the responsibility of Health – however there are a number of disability-related health supports that the NDIS does fund.

<https://www.ndis.gov.au/understanding/supports-funded-ndis/disability-related-health-supports>

Information about the NDIS and COVID19 for participants NDIS

<https://www.ndis.gov.au/coronavirus/participants-coronavirus-covid-19>

Eligibility for and application to the NDIS:

<https://www.ndis.gov.au/applying-access-ndis/am-i-eligible>

Providing evidence of disability for an NDIS application:

<https://www.ndis.gov.au/applying-access-ndis/how-apply/information-support-your-request/providing-evidence-your-disability>

NDIS Plan Review - when support needs have changed:

An admission to hospital may be associated with a change in the person’s ongoing support needs. For more information:

<https://www.ndis.gov.au/participants/reviewing-your-plan-and-goals/who-needs-plan-review>

Feedback and Complaints:

<https://www.ndis.gov.au/contact/feedback-and-complaints>

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Clinical Guideline 1: Understanding behaviour change in people with an intellectual disability or autism spectrum disorder within a healthcare context.

A person with an intellectual disability or autism spectrum disorder will have particular patterns of behaviour that are normal for them. Those who know the person well (family, carer or support staff) will be able to tell you how the person usually behaves, how they appear when they are calm, how they show discomfort, pain or fear, and how to best work with them to support them to feel safe and calm.

Causes for behavioural change

A change in a person's usual behaviour communicates a change in the person's needs, comfort or wellbeing and usually indicates a change in:

- Physical health
- Mental health
- Sensory sensitivity or loss
- Life circumstances or environment (e.g. death or illness of family member, friend, peers or housemate; changes of staff at day activities or home; a new housemate moving in; new staff)

Examples,

- *Appendicitis may present with someone expressing their pain by screaming, curling up in bed, refusing to stand.*
- *Depression may present with changes in appetite, sleep, mood (crying, irritability, not joking/laughing), anhedonia and social withdrawal.*
- *Hearing impairment may present with someone not responding to verbal engagement or requests, or a reluctance to participate in social gatherings.*
- *A recent change at the person's home (e.g. a family member, housemate, or favourite staff member leaving) may lead to feelings of loss and grief. This may be expressed as crying, irritability, anger and/or perhaps even threatening or assaultive behaviour.*

Physical illness, pain or discomfort

When assessing someone with a disability in a healthcare setting, consider:

- What conditions would you consider in **any patient** of this **age** and **gender**?
- What conditions are known to be more common in people with **intellectual disability**? (Examples include sensory impairment, oral/dental disease, GORD, constipation)
- What conditions are known to be more common in people with **disability from this particular cause**?

(Examples include: hypothyroidism in people with Down syndrome, reflux oesophagitis in people with Cornelia de Lange syndrome, psychosis in people with Prader Willi syndrome)

- Could **medications** be causing adverse effects? (Examples: the person may stop eating because of nausea, refuse to walk because of dizziness or blurred vision, or become agitated, sedated or confused because of effects on cognition)

Mental illness or distress

- Disorders of mental health are **more common** in people with intellectual disability. Bio-psycho-social factors all increase the risk for mental ill health.
- Look for the '**behavioural equivalents**' of depression, anxiety, bipolar disorder, or psychosis (Example: social withdrawal; not attending or enjoying previously favourite activities (anhedonia); crying, irritability, not joking/laughing as much (mood); sleep and appetite changes (somatic) could suggest depression).
- Consider emotional, physical and/or sexual abuse.

Sensory sensitivity or loss.

- Ask about **sensory sensitivities** (hyper-sensitivity and reactivity to the visual, auditory, olfactory, or tactile stimuli). Individuals may find such stimuli highly aversive, even painful, or, alternatively, highly pleasurable or calming.

A quiet place with fewer auditory, visual and olfactory stimuli may help people feel more relaxed while waiting and enable you to better assess and examine them.

- Has there been a **deterioration** in the person's vision or hearing? Many people with disabilities have impaired hearing and/or vision. They may not be able to report a change, but their behaviour may reflect a lack of acuity, reduced responses or resulting confusion or uncertainty.

Changes in life circumstances or environment:

Ask about:

- Where they live and with whom? What support do they need and who provides it?
- What do they do during the day?
- Who are their family and friends?
- Have there been any changes in their life circumstances or relationships that have a temporal relationship to the onset of their change in behaviour?

Clinical Guideline 2: Admission of people with an intellectual disability or autism spectrum disorder to acute health services.

This information is designed to assist health professionals care for their patients who have intellectual disabilities or autism spectrum disorders.

Monash Health is located within a large and diverse community. Health professionals work across this community with many different patient groups, including people with intellectual disabilities or autism spectrum disorders. When a patient with an intellectual disability or autism spectrum disorder is **admitted to hospital**, there are some important issues to keep in mind.

Reason for admission

The admission could be for any (or combination) of the following reasons:

- Known or suspected health issue (physical or mental health)
- Procedure (including investigation or surgery)
- Change in behaviour for investigation
- Need for additional support and services (including breakdown of accommodation)

Communicating information regarding the admission

- **If the admission is planned**, care givers may be able to reduce anxiety by **preparing** the patient with information about what they are likely to experience while in hospital. This may take the form of visual aids such as stories with pictures (social stories). A visit to the health service beforehand may also be useful both for familiarity and to take pictures for the visual aid.
- **On admission**, ensure the **reason for the admission** been explained to the patient using their preferred manner of communication? This may include clear language, pictures, gestures, sign language (they may need an Auslan interpreter). Encourage the patient to ask questions, using their communication aid/device if they have one.
- People with disability will often have **support plans** for behaviour or specific physical conditions (such as oral care, epilepsy) that guide their care at home. Ensuring these are available to hospital staff on admission is important to ensure understanding and addressing the person's needs and providing continuity of care.

Medical decision-making

Consider:

- Is the patient able to make their own decisions in relation to medical care?
- How does the patient express their choices and decisions?
- If the patient requires support to make decisions, who provides this support?

- Does the patient have a nominated Medical Treatment Decision Maker?

For further information see 'Can your adult patient consent?':

<https://www.publicadvocate.vic.gov.au/resources/flowcharts/341-can-your-adult-patient-consent-flowchart?path=>

Understanding the patient

- **Admission to hospital is a stressful** event for anyone. This may be particularly so if the patient has cognitive and/or communication impairments.
- **All patients** have a right to be valued, listened to, supported to be as independent as possible, and to have their dignity respected, regardless of cognitive or communication ability.
- **Behaviour:** Ask about the patient's **usual demeanour**, level of alertness, mood, behaviour, communication, cognitive, motor and sensory ability. Ask of this has changed, if so **how** and **when**?
- **Communication: How does the patient usually communicate?** How can their **independence in communication** be supported? Does the patient have a communication aid (for example: iPad, board, book)? If so, how do they use it? **This must be available to them at all times while in hospital.**
- **Mobility: How has does the patient usually move around?** How can their independence in mobility be supported? Do they use a mobility aid? Discuss with them what would be best for them to use in hospital.
- **Personal care:** What aspects of personal care do they manage themselves and what do they need assistance with? How would they like that assistance provided?
- Ask about their **strengths and abilities as well as what the person finds difficult.**
- What are their preferences, interests, likes and dislikes relevant to care in hospital.
- **How has the patient coped with previous hospital admissions?** How can the patient be best supported to feel as safe and comfortable as possible on this admission? (Visits from familiar people, visual cues, favourite routines, precious objects, minimising sensory overload such as lights, noise or smells, providing as much predictability and consistency in care as possible).

Taking a detailed history

- Always **speak to the patient** and obtain as much information directly from them as possible. If they are not able to provide information, include them in the discussion through non-verbal means including eye contact and using their name.
- If required and with consent, gather additional information from those who know them well; you may need to ring family members or senior support staff at the person's home

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and/or work/school/day placement, their GP, and other services providing support and care.

- **Comprehensively document** all the patient's health conditions, support plans (e.g. oral care, foot care, epilepsy, behaviour), and current medications to ensure management in hospital addresses all of the patient's health needs and care is consistent.
- **Ask to see the patient's health file**; many families and all supported accommodation facilities keep an individual health file.
- Consider **conditions that you would look for in any other patient** of that **age or gender** (for example malignancy in an older person with weight loss).
- Consider **conditions are known to be more common** in people with **disability from this particular cause?** (Examples: hypothyroidism in people with Down syndrome, reflux oesophagitis in people with Cornelia de Lange syndrome)

Helpful website include:

<https://rarediseases.info.nih.gov>

<https://rarediseases.org/rare-diseases>

<http://www.geneticalliance.org.au>

<https://www.vcgs.org.au>

Assessing support in the community

GP

Many people with disabilities have a close relationship with their GP. Contacting the GP practice:

- Alerts them to the admission, and
- Provides information relevant to admission.

Accommodation

- Where does the patient live? With whom?
- What support do they need in their daily life and who provides it? These people are an essential part of the care team, and **must be engaged** as partners in care for admission, inpatient care and discharge planning.

Family

Are family members present?

- If so, ask them if the patient has presented like this before? If so, what was the diagnosis then? What worked and what didn't work during their last hospital stay?
- If not, ask the patient if they would like them notified. They can be an important source of further information if the patient has difficulty providing their own history.

Paid support staff

- Are direct care support staff present?

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- If so, how well do they know the patient? Ask them if the patient has presented like this before. If so, what was the diagnosis? What worked and what didn't work during their last hospital stay?
- If not, ask the patient if they would like them notified. They can be an important source of further information if the patient has difficulty providing their own history.

NOTES:

1. **Direct support staff are experts in supporting people with disability and their perspective and expertise is invaluable.** They are not health professionals so use plain English and avoid assuming health knowledge and using health jargon.
2. **Paid staff are not permitted to consent on behalf of the person.** If the person themselves is not able to give informed consent, then the Medical Treatment Decision Maker must be identified and contacted (unless in an emergency). See Flow Chart at <https://www.publicadvocate.vic.gov.au/resources/flowcharts/341-can-your-adult-patient-consent-flowchart?path=>
3. **Respect the patient's privacy** while taking into account the support they need to engage with health services.

Undertaking an examination and investigations

- Always **establish rapport** before asking the patient's permission to examine them and explain to the patient what you are going to do **BEFORE** doing it.
- **Ensure patient is provided with an explanation** using their preferred manner of communication. This may include clear language, pictures, gestures, sign language (you may need an Auslan interpreter). Encourage the patient to ask questions using their preferred communication method – communication aid/device, sign language.
- **Check understanding** by asking the patient to explain to you in their own words the key information you have tried to convey.

NOTE: When a patient is not able to describe their symptoms or their response to treatment, a comprehensive head to toe **examination**, and appropriate **investigations**, **play an even more essential role** in identifying pathology and clarifying the diagnosis than is the case when patients can provide a clear history.

Clinical Guideline 3: Inpatient care of people with an intellectual disability or autism spectrum disorder in acute health services.

This information is designed to assist health professionals care for their patients who have intellectual disabilities or autism spectrum disorders.

Monash Health is located within a large and diverse community. Health professionals work across this community with many different patient groups, including people with intellectual disabilities or autism spectrum disorders. When a patient with an intellectual disability or autism spectrum disorder becomes an inpatient, there are some important principles to keep in mind.

Understanding the patient and their health issues

- All individuals have **unique life experiences and areas of ability** and disability. Some people live independently; others are supported by family or community services; while others are supported by disability trained direct support staff in shared homes.
- **Every person is unique; each with his/her own likes, dislikes, interests**, preferred activities, and ways they demonstrate and cope with stress or pain.
- People with intellectual disability often have other functional and health issues including **motor** impairments (speech, mobility, fine motor), **sensory** impairments (vision, hearing, sensation), **epilepsy**, disorders of **mental health** (for example, depression, anxiety), **oral or dental disease** and **gastrointestinal issues** (for example, reflux, constipation).
- Patients are often on multiple **medications** and may have difficulty reporting adverse effects.
- Patients with disability may have missed out on **health promotion or disease prevention health** messages and interventions (for example: nutrition, exercise, immunisation, cancer screening).
- If someone has **communication** difficulties, s/he is more likely to have undiagnosed or misdiagnosed health issues than the general population.
- **Admission provides an opportunity** to assess and clarify the patient's current health issues and establish a comprehensive management plan to support optimal health in the community after discharge.

Communicating with the patient, family or direct support staff

- Ask about the patient's **usual demeanour**, level of alertness, mood, behaviour, communication and cognitive, motor, and sensory ability. **What has changed**, how and when?

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- Ask about the patient's **strengths and abilities** and what they find difficult, as well as their preferences, likes and dislikes relevant to care provision.
- Ask about the patient's **communication** preference. Does the patient use a communication aid, equipment or device (for example, iPad, board or book)? How do they use it? **This must be made available to them at all times while in hospital.**
- Does the patient have **mobility** issues? Do they use a mobility aid? Discuss what would be best for them to use in hospital.
- How can the patient be **best supported** to feel as safe and comfortable as possible? This may include visual cues, favourite activities and routines, and/or objects; minimising sensory overload (lights, noise, smells); and providing as much predictability and consistency in care as possible.

- Some people may need the health service to provide 1:1 care for part or all of the period of admission. In some instances, family members, close friends or direct support staff may be available to stay with the patient for some or all of their hospital stay. Their knowledge of the person may help overcome communication difficulties and provide reassurance and comfort to the patient.

Predictability and consistency

- Hospitals have rules, rhythms, sights, sounds and smells which are very different to the home environment.
- Hospitals can be frightening places for anyone, and particularly for people particularly sensitive to the **sensory environment**, who have difficulty understanding hospital routines and expectations, why they are there and what is going to happen to them.
- Providing **clear information**, minimising sensory stimuli, and maximising **predictability** (e.g. daily schedule) and **consistency** of care (same staff as much as possible) will support the person to feel as safe and secure as possible while an inpatient.

Helping the patient to adjust to the hospital environment

- **Learn how the patient communicates** and make every attempt to communicate in a meaningful way with them.
- **Appreciate how people may express their distress or discomfort** (whether related to physical pain, anxiety or the environment) through a change in their behaviour.
- **Speak to the patient** directly and explain what is happening and what will happen next. It is often helpful to use pictures.
- **Provide predictability and consistency** in your care as much as possible. This could include assigning the same staff each day, making visual timetables of the day and using the same key phrases when approaching the patient for particular tasks.

- **Work in partnership** with those who know the person (family, disability staff) and with those supporting the patient in hospital (whether hospital staff, family or disability staff) to understand and meet their needs.
- **Understand the patient's sensitivity** to certain smells, light, sounds, touch or tastes and, as much as possible, reduce aversive stimuli and provide a calm and quiet environment.

Key points:

Care in hospital includes:

- Building **rapport** and **communicating** directly with the patient.
- Valuing the **knowledge and experience** of those who know the person well (family, friends, direct support staff) and working closely with them.
- **Learning** how to best communicate with the patient (communication aids, devices)
- Understanding how the person may **express their distress** or discomfort through a change in behaviour. Be aware that some of behaviours exhibited while in the hospital maybe due to the hospital environment itself rather than an indicator of significant psychological deterioration
- Addressing the person's **multiple health issues**.
- Providing as much **predictability and consistency** as possible.

Clinical Guideline 4: Discharge planning from acute health services for people with an intellectual disability or autism spectrum disorder.

This information is designed to assist health professionals care for their patients who have intellectual disabilities or autism spectrum disorders.

Monash Health is located within a large and diverse community. Health professionals work across this community with many different patient groups, including people with intellectual disabilities or autism spectrum disorders. When a patient with an intellectual disability or autism spectrum disorder **is discharged from hospital**, there are some important principles to consider.

Supporting the patient in healthcare planning

- All individuals have **unique life experiences and areas of ability** and disability. Some people live independently; others are supported by family or community services; while others are supported by disability trained direct support staff in shared homes.
- Many require **support for daily activities**, including the organisation of healthcare appointments and following through on management recommendations. This support is often provided by family members and/or paid disability direct support staff. Direct support staff are experts in supporting people with disability; they do not have health training.
- **Detailed discharge planning** for care at home is necessary to ensure all those involved have the training, capacity and ability to provide the care required, and the information and resources they need to do so.
- The **GP** will play a central role in providing care in the community and must be made aware of the discharge. A copy of the Discharge Summary (see below) **must be faxed or emailed** to the GP **upon discharge**.

Arrangements for discharge

- Consider the patient's **needs at home and who will provide** that support.
- **Ask about the availability of support and work with those who will provide that support to ensure a successful discharge. For people in group homes**, avoid discharging patient on Friday or over the weekend if possible.
- Is the patient **physically ready** for discharge? E.g. IV lines removed, wounds dressed.
- Does the patient require monitoring and recording of **seizures**? Has this been explained to carers?

- Does the patient require assistance in monitoring and dressing **wounds**? Has this been explained to carers?
- Does the patient need assistance in arranging and attending **follow up** investigations and appointments? Has this been explained to carers?
- Does the patient have **transport** home? Has this been discussed with carers?
- **Has the patient's functional ability changed** during the admission? This may include: independence in personal care, community access, mobility and/or communication. Has this been taken into account when organising support and therapy post discharge?
- Does the patient require support for **personal care**, shopping (including chemist for medications), meal preparation and other domestic tasks? Has this been taken into account when organising support post discharge?
- Does the patient or carer(s) require arrangements to be made for **home modifications**, provision of equipment or training for aids or equipment?
- **Have clear arrangements been made and communicated** to the patient and those supporting him/her for follow up and ongoing care, eg rehabilitation (eg. physio).

Medication on discharge:

- **Disability staff are not medically trained**, therefore, indications for the use of all medication, particularly PRN medication, need to be very clear with specific instructions on when and how it is to be used. If disability support staff are administering medications an **updated medication chart must be completed PRIOR to discharge** to ensure no discontinuity of medication. Many people, including those who live in group homes, will require the preparation of a Webster pack for their medication post-discharge. Has this been discussed with the patient's pharmacist and the necessary paperwork provided to enable the medication to be available when the patient goes home.
- **Appropriate formulation** of medication may need to be discussed and planned with the pharmacist prior to discharge. Will patient be able to swallow medication? Can the patient swallow tablets without chewing them? Can the patient manage the consistency of liquid medication without risk of aspiration? Is formulation suitable for G tube? (If it's too 'grainy' it can damage the PEG button). Flavour and or texture will be very important to some individuals and administration may not be possible at home if these factors are not addressed. If there are **specific instructions** in relation to the formulation or administration of medication, have these been communicated to **both the carers and the GP**?
- Does the patient require assistance with administering **medication** and **monitoring** for adverse effects? Who will be responsible for this?

Discharge Summary

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Discharge information regarding admission and care needs must be communicated clearly, both **in person and in writing**, to both the patient and those supporting them at home/ in the subacute setting, **as well as to the GP**.

If there is a delay in providing the Discharge Summary, an **Interim Discharge Summary is required** to ensure those providing care, including the GP, have the information and contacts they need to ensure good post-discharge recovery. Any particular issues experienced during the admission should also be described.

The Discharge Summary (and Interim Discharge Summary) must be clear, self-explanatory, use Easy English terms (not medical jargon) and include:

- The **diagnoses**.
- The **presentation** and **assessments** undertaken.
- **Management**, response and expected progress.
- **Medications** on discharge and information about medication management plan including dose, length of treatment and common side effects.
- Arrangements for **follow up**.
- **Contact** numbers for questions and concerns.

Key points:

- **The key to good discharge is good planning and communication with all concerned.**
- **Plan discharge in partnership with those who will provide day to day personal support and those who will provide ongoing healthcare (GP, nursing services, therapists etc.) Document implications of health issues identified for ongoing management and provide a copy to carers and GP.**
- **A Discharge summary must be provided to the person/carers and the GP on discharge.**

Clinical Pathway/Flow Chart/Algorithm

The following Assessment and Management Framework has been developed by the Centre for Developmental Disability Health

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Assessment and Management Framework

Behaviour Change in People with Intellectual Disability

Presentation

Exactly what happened:

- **STAR:** Settings, Triggers, Actions, Results OR
- **ABC:** Antecedents, Behaviour, Consequences



Beware of interpretations:

- e.g. “withdrawn”, “aggressive”, “destructive”
“non-compliant”, “attention seeking”, “manipulative”.

Context

Safety

Person, others.
Immediate, imminent.



Communication

Expressive and receptive ability.
Preferred methods and equipment.

Person

Usual behaviour, personality, abilities, challenges.
Cause of disability (behavioural phenotype?)

Support network

Family and paid support workers -
knowledge, concerns, perspective.

Assessment and Provisional Diagnosis

Physical health

Symptoms, age and gender, aetiology of disability.
Physical examination.



Sensory issues

Consider sensory loss.
Altered sensory thresholds (increased or decreased).

Mental health

Anxiety, depression, mania, psychosis, bipolar disorder.

Life circumstances

Environment: social, physical.
Life events: change, transition, grief.

Initial Management

Further history. Behaviour recording.
Investigations and referrals.



Intervention:

- Non-pharmacological.
- Pharmacological.



Evidence on which this clinical guideline is based

Clinical Guidelines: (eTG) Management Guidelines: Developmental Disability. Version 3. Melbourne: Therapeutic Guidelines Limited; 2012.

NICE Guidelines:

- **Autism spectrum disorder** in adults: diagnosis and management
Clinical guideline: [CG142] Published date: June 2012 Last updated: August 2016
www.nice.org.uk/guidance/CG142
- **Challenging behaviour and learning disabilities:** prevention and interventions for people with learning disabilities whose behaviour challenges
NICE guideline Published: 29 May 2015 nice.org.uk/guidance/ng11

Expert consensus: Centre for Developmental Disability Health; Stronger Together Mental Health Service for People with Intellectual Disability.

Trollor J, Srasuebku P, Xu H, *et al.* **Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data**
BMJ Open 2017;**7**:e013489. doi:10.1136/bmjopen-2016-013489

Consent for medical procedures: Office of the Public Advocate:
www.publicadvocate.vic.gov.au/medical-consent

Linkage to Procedures/Medication Profiles/Implementation Tools

<http://prompt/Search/download.aspx?filename=1824321\1824323\24417370.pdf>

Keywords or tags

Disability, intellectual disability, autism, autism spectrum disorders, behaviour

Document Management

Unit/Service/Person responsible for document development: Director, Centre for Developmental Disability Health

Person accountable for clinical content: Director, Centre for Developmental Disability Health

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Updated by:

Dr Jane Tracy

Policy supported:

- **Safe, Effective Patient Centred Care**

<http://prompt/Search/download.aspx?filename=1407793\17368795\19865978.pdf>

- [Evidence-Based Clinical Care \(Operational Policy\)](#)

<http://prompt/Search/download.aspx?filename=1407793\17368795\29316971.pdf>

- **Acute Disturbed Behavioural Disturbance Guideline:**

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Executive sponsor: Danielle Ryan, Operations Director, Community (Interim) | Monash Health Community & Allied Health | Monash Health

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