



INFORMATION FOR PRIMARY HEALTH CARE STAFF

21 May 2020

SUPPORTING PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITY DURING THE COVID-19 PANDEMIC

This fact sheet is for primary health care staff and services, including general practitioners (GPs), providing health care to people with intellectual or developmental disability during the COVID-19 pandemic.

Are people with intellectual or developmental disability at greater risk of COVID-19?

People with intellectual or developmental disability:

- are highly vulnerable groups and often have complex comorbidities and pre-existing health conditions. These groups experience very high mortality rates and reduced life expectancy. Many deaths are due to potentially avoidable causes
- can experience difficulties accessing appropriate health care and some conditions may be undiagnosed or undermanaged
- and those around them may have an increased risk of infection and transmission due to comprehension, communication and behavioural issues
- have high rates of mental health and behavioural issues. The COVID-19 pandemic may exacerbate these because of extra stress around changes in routine, supports and community access.

Respiratory disease and infections are among the most common causes of death in people with intellectual disability.

This means that some people with intellectual or developmental disability with certain risk factors may be at higher risk of:

- **acquiring** COVID-19
- **serious illness** due to COVID-19.

It is important to:

- consider these vulnerabilities
- consult relevant specialists
- make reasonable adjustments to enhance health outcomes for these groups
- uphold the human rights of people with disability to equitable, accessible and tailored health care.

What role can primary health care play?

Primary health care services provide critical services to people with intellectual or developmental disability. During the COVID-19 pandemic, this includes routine health care and health care related to COVID-19.

A person's regular GP and primary health care services are likely to:

- have extensive pre-existing knowledge about the person
- be familiar with their support setting and their health vulnerabilities
- be critical in coordinating the person's health care during the COVID-19 pandemic
- have a key role in transmitting the person's health information to others involved in COVID-19 prevention, testing and treatment if necessary
- be aware of specific vulnerabilities and necessary adjustments to enhance access to services and clinical outcomes for these groups.

How is the risk of COVID-19 different for people with intellectual or developmental disability?

Potential factors which may increase the risk of people with intellectual or developmental disability **acquiring and transmitting** COVID-19 are that they may:

- live in communal, custodial or residential care settings
- need close proximity in support (e.g. assistance with feeding and other aspects of physical care)
- have multiple people involved in providing support
- have difficulty understanding and adhering to social distancing, handwashing and other risk reduction strategies
- engage in behaviours that may increase the risk of COVID-19 acquisition or transmission.

Potential factors which may increase the risk of people with intellectual or developmental disability experiencing **serious illness** due to COVID-19 include:

- difficulty accessing usual medical care, increasing the risk of serious illness relating to pre-existing conditions
- [certain medical conditions and co-morbidities](#).

What to consider when providing routine health care during the COVID-19 pandemic

When delivering routine health care for a person with intellectual or development disability during the COVID-19 pandemic, primary health care staff should:

- discuss how and when you will provide care during the pandemic. For example, when home visits, telehealth and face-to-face consultations will be used
- conduct a [health assessment for people with an intellectual disability](#) or update the patient's care plan where appropriate. Provide a copy to the patient and their family or disability worker, and upload a shared health summary to My Health Record
- ensure vaccinations for influenza and pneumonia are up to date
- inform the person with disability about COVID-19 in a way that's accessible and they can understand
- consider the potential impacts on the health of the person's whole family, especially for children.

What to consider when assessing people with intellectual or developmental disability

When assessing a person with intellectual or development disability, primary health care staff should:

- conduct a detailed review of the health and disability information that came with the person. This may contain important information about:
 - what is normal for the person
 - how to support access to health care
 - their communication preferences
 - their medical history, allergies and current medications

- be aware of late and/or atypical presentations. Some symptoms may be reported or present differently (e.g. changes in behaviour) or the disability or treatments may impact the symptoms (e.g. no fever present due to medications or altered inflammatory responses). A thorough assessment will reduce the risk that important health issues are not identified or are misdiagnosed
- maximise involvement of family members and/or disability workers. These people are likely to be familiar with the symptoms that indicate illness or the person's condition deteriorating. They can also assist in managing any anxiety, confusion or stress
- allow extra time for clinical interaction and observation due to the level of complexity of health, disability and communication needs
- adjust your communication and use resources appropriate to the person to ensure that communication is accessible and understood. **Note:** wearing PPE may cause fear and anxiety and could compound communication issues. You may need to repeat explanations using Easy Read resources
- monitor the person's mental wellbeing and behaviour for impacts of the pandemic
- where possible, anticipate and plan for emerging health issues, such as seasonal influenza.

What to consider when making treatment decisions

When making treatment decisions for a person with intellectual or development disability, primary health care staff should:

- make treatment and health care decisions according to best practice principles. Don't make assumptions about the quality of life of people with disability
- relevant national, state and local guidelines relating to COVID-19
- support adults with intellectual and developmental disability to make their own medical decisions as much as possible. If the person is unable to consent, follow substitute decision laws
- take into account the potential for the patient's health to rapidly deteriorate due to pre-existing complex comorbidities and/or potential late or atypical presentation
- consider the risk to staff and others, including from challenging behaviour and lack of adherence to protective measures. Services need to factor these issues into acuity assessments and infection risks
- implement additional appropriate infection control measures. Family and disability workers may be present and disability-related equipment such as wheelchairs, communication devices and aids, indwelling catheters, etc may be in use

- reduce barriers to access health care for these groups. Consider the use of [Telehealth MBS items](#), home visits and [Bulk Billing incentives](#)
- consider, if available, alternative testing methods for those unable to tolerate nasopharyngeal swabs
- manage the person's condition in the environment which maximises safety and adherence to medical treatment. This may be a 'hospital in the home' type arrangement in some cases
- consider the potential impact of illness in a family member or disability worker who usually provides support. This may trigger a need to mobilise alternative supports
- Consider if there is a need to rapidly mobilise additional disability supports to support implementation of preferred health care arrangements.

Where can I get more information?

For the latest health advice, information and resources on the COVID-19 pandemic, go to www.health.gov.au. For additional information specific to people with disability during the COVID-19 pandemic, go to <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>.

An Intellectual and Developmental Disability Health Working Group convened by 3DN, UNSW Sydney prepared this fact sheet.