

# ALTERNATIVE APPROACHES FOR COVID-19 TESTING FOR PEOPLE WITH DISABILITY

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## Purpose

The purpose of this paper is to identify challenges faced by people with disability in accessing COVID-19 testing and propose solutions to improve their access to testing and reduce the risk of transmission.

The target audience includes people with disability, carers, services providers, primary care physicians (GPs), health services, public health units and peak disability groups.

## Introduction

- Functional impairment and disability have diverse impacts on an individual's ability to meet their daily needs.
- The ability to detect cases of COVID-19 is central to the strategies that are being used to prevent ongoing community transmission in NSW.
- A high rate of well-targeted testing is essential to reducing community transmission of COVID-19.
- Understanding barriers to testing and the means to facilitate testing is important. Tailored solutions that consider an individual's unique circumstances are needed to ensure equitable and appropriate access to healthcare for people with disability.

## Barriers and Susceptibility to Testing

For those with disability, barriers to testing include:

- difficulties in communicating COVID-19 symptoms/illness to others
- difficulties of carers identifying subtle symptoms (e.g. loss of appetite, lethargy, changes in sense of smell or taste) or interpreting changes in behaviour (increased desire to sleep, irritability, agitation, withdrawal) in individuals with communication barriers

- challenges for people with vision, hearing or other communication impairment (receptive and expressive) to communicate with testing staff wearing masks
- lack of accessible testing clinics to accommodate physical, communication and psychosocial needs for people with disability
- lack of visibility of alternatives to testing via a testing clinic

Testing difficulties for people with disability are further compounded by an increased susceptibility to COVID-19 or risk of severe disease for some individuals because of:

- pre-existing illness and/or other co-morbidities
- living in congregate care arrangements – many people with disability live in group residential settings and receive close personal care from multiple staff, increasing the risk of acquiring COVID-19 infection
- inability to physically distance, increasing the risk of exposure and infection, including:
  - o many people with significant disability have a high level of engagement with service providers and/or mobility issues and which prevents them maintaining physical distance
  - o people who are vision impaired may not be able to identify when others are within 1.5m
- age – as people age, their susceptibility to developing disability increases as does their risk of developing severe COVID-19 related illness
- isolation requirements – some people with disability may also experience increased difficulties due to isolation requirements (including psychological stress) and require more targeted support

Many people with a disability are reliant on in-home service providers or unpaid carers for their essential daily care, which may or may not require specialised skills. If an individual is COVID-19 positive or suspected of being

COVID-19 positive, those services may be disrupted because:

- care providers may be reluctant to continue delivery of care and/or reduce services
- usual carers may have to isolate themselves
- new care providers may be unfamiliar with/not understand the specific needs of those receiving care
- service provision may become more difficult because care providers have to wear full personal protective equipment

Service disruption risks leaving the person with disability vulnerable and at high risk of hospitalisation or neglect of basic needs. It is important for COVID-19 testing providers to be aware of the needs of the person with disability, the level of services they require and whether they are still being provided. Based on this risk assessment, COVID-19 testing providers should ensure:

- specimen collection is performed as soon as possible after symptoms appear, and
- processing is prioritised to minimise disruption to essential services.

The barriers and proposed approaches are detailed in **Appendices 1 and 2**, respectively.

## Current Testing Options in NSW

Access to COVID-19 testing is primarily through testing clinics. Current options in NSW include:

### Fixed clinic or rapidly deployed pop-up clinic

- in-person or drive-through testing at a COVID-19 testing clinic - NSW Health public hospital Emergency Departments, NSW Health public COVID-19 clinics, Australian Government GP respiratory clinics or private testing collection services
- in-person at some GP practices
- temporary rapidly deployed pop up clinic

### Home collection service

- a limited number of private pathology providers offer a home-collection service for COVID-19
- Hospital in the Home (HITH) or other outreach services (frequently with limited capacity) may be able to take nose and throat samples

NSW Health Pathology does not recommend self-collection as the preferred method for sample collection and it should only be performed with instruction from a health care worker<sup>1</sup>

## Standard approach to testing

NSW Health Pathology recommends pathology samples to test for SARS-CoV-2 be attained through an appropriately collected upper or lower respiratory tract swab.

The current standard set by NSW Health Pathology is both throat and bilateral deep-nasal swab sampling which is then tested on a variety of platforms<sup>2</sup>. Alternative specimen collection, such as saliva testing is less sensitive<sup>3</sup>. For this reason, saliva testing is not currently recommended as a routine diagnostic testing approach.

## Alternative testing solutions

The alternatives to standard COVID-19 testing are considered in **Appendix 2** and include:

- home testing by a health care worker or trusted carer<sup>4</sup> under the instruction of a health care worker<sup>5</sup>
- less invasive COVID-19 testing approaches (for example, saliva specimen) - noting that a Doherty Institute study<sup>6</sup> found that saliva testing missed 13% of infections found on nasopharyngeal swabs
- do not test but manage the patient as a presumptive case

1. [Clinical advice on self-collection of swabs for COVID-19 testing](#)

2. [Polymerase chain reaction \(PCR\) and/or nucleic acid testing \(NAT\)](#)

3. That is, less able to accurately detect COVID-19 in someone who is infected

4. A 'trusted carer' is a person who provides unpaid care and support to people with disability including family members or friends

5. Health care worker collection of the specimen is preferred. If self-collection is used, NSW Health Pathology recommends that it should be done under instruction of a health care worker

6. Williams E, Bond K, Zhang B, Putland M and Williamson DA. [Saliva as a non-invasive specimen for detection of SARS-CoV-2](#), Journal of Clinical Microbiology, posted Online 21 April 2020

The type of testing service utilised will depend on the individual circumstances of the person with disability. The testing options should be discussed and decided in collaboration with the person with disability, their personal support team including their GP, service provider, the local public health unit and, if necessary, the Public Health Response Branch.

The ongoing daily needs and continuation of essential services of the person with disability must be prioritised and supported.

## Proposed approaches to testing

### 1. TAILOR SOLUTIONS

#### Tailor the solution to the nature of the impairment

For example:

- for those with access difficulties - improve the capacity of fixed services to support people with mobility, communication, psychosocial or sensory needs, widen availability of in-home services (e.g. a commitment by HITH in each Local Health District (LHD), identify and organise private pathology lab home collection services)
- where the use of masks impedes communication (e.g. in people with hearing impairment) or creates anxiety (e.g. for people with psychosocial or intellectual impairment) face shields (with chin surround) and/or clear face masks could be considered (availability to be determined)
- consideration of collecting alternative specimens where a nose and throat swab is not possible - including collaboration with trusted carers (instructed in conducting swabbing by telehealth), GPs and local infectious disease clinicians
- use of familiar persons (e.g. GP, trusted carer) to assist in the collection of the specimen in a safe and supportive environment

7. For example, a printed flyer may be effective for people with hearing or vision impairment to provide to their GP but direct communication with people with disability will need to consider the different modalities required - video, audio, captions, Auslan, scripts/documents suitable for screen readers, Easy Read versions, cultural and linguistically diverse versions etc. Consideration should also be given to the role of health sector and other stakeholders in disseminating information including the Primary Health Network, public hospitals, community health services, Health Consumers NSW and Carers NSW.

### 2. WORK COLLABORATIVELY

**Testing clinics and health professionals should work with carers to support meeting the health needs of people with disability, including accessing a COVID-19 test and the continuation of essential support services they receive.**

### 3. COMMUNICATE EFFECTIVELY

#### Develop a communication strategy that meets the needs of people with disability

An accessible communication strategy will include:

- CO-DESIGN - identifying, developing and disseminating relevant and accessible information to people with disability and their families, disability advocacy services and park groups, GPs, COVID-19 clinics, disability service providers and community members relevant to the testing approaches<sup>7</sup>
- TARGET ACCESSIBILITY - working with stakeholders to determine:
  - o the methods of communicating that best meet the needs of people with communication challenges, including those associated with vision, hearing, deaf-blind, cognitive disability, autism and psychosocial disabilities - as well as combinations of multiple disabilities, and
  - o advice on when and how each approach might be used
- MONITOR AND SEEK FEEDBACK - ensuring that:
  - o health services continuously monitor the delivery of testing options, and
  - o feedback mechanisms are available that are accessible to people with disability to ensure the effectiveness, efficiency and adaptability of both:
    - (i) the testing options, and
    - (ii) the communication products

## Appendix 1: Barriers to COVID-19 testing for people with disability\*

\* NB: Additional complexities may arise where individuals experience multiple disabilities

Domain	Example impairments	Challenges of testing
Mobility/ motor	Motor disorders	<ul style="list-style-type: none"> <li>Accessing a clinic e.g. building accessibility, accessible travel</li> <li>Communicating with healthcare workers where there is additional communication impairment</li> </ul>
	Paraplegia/quadruplegia	<ul style="list-style-type: none"> <li>Accessing a clinic e.g. building accessibility, accessible travel</li> </ul>
Sensory	Profound deaf (lifelong)	<ul style="list-style-type: none"> <li>Understanding verbal COVID-19 health advice</li> <li>Communicating with healthcare workers - especially if testing staff are wearing masks and/or Auslan interpreter is not available in the health facility</li> <li>Requirement for person with disability and their support staff to use a mask</li> </ul>
	Progressive deafness	<ul style="list-style-type: none"> <li>Understanding verbal COVID-19 health advice</li> <li>Communicating with healthcare workers - especially if health care workers are wearing masks</li> <li>Requirement for person with disability and support staff to use a mask</li> </ul>
	Profound blind (lifelong)	<ul style="list-style-type: none"> <li>Accessing a clinic e.g. building accessibility, accessible travel</li> <li>Access to written COVID-19 health advice and forms</li> </ul>
	Progressive blindness	<ul style="list-style-type: none"> <li>Accessing a clinic e.g. building accessibility, accessible travel</li> <li>Access to written COVID-19 health advice and forms</li> </ul>
	Deaf/blind	<ul style="list-style-type: none"> <li>Accessing a clinic e.g. building accessibility, accessible travel</li> <li>Limited or no access to written and/or verbal COVID-19 health advice</li> <li>Communicating with healthcare workers - especially if testing staff are wearing masks and an appropriate interpreter is not available in the health facility</li> <li>Requirement for individualised one-on-one support to understand COVID-19 health advice and facilitate communication with person with disability</li> </ul>
Psychosocial	Mood disorders	<ul style="list-style-type: none"> <li>Communicating with healthcare workers</li> <li>Disordered thinking affecting beliefs about the pandemic</li> <li>Lack of motivation</li> </ul>
	Anxiety	<ul style="list-style-type: none"> <li>May fear leaving home to access clinic</li> <li>Fear of the test</li> <li>Agitation</li> <li>Communicating with healthcare workers</li> </ul>
	Psychosis	<ul style="list-style-type: none"> <li>Disordered thinking affecting beliefs about the pandemic</li> <li>Behaviours of concern</li> <li>Communicating with healthcare workers</li> </ul>

Domain	Example impairments	Challenges of testing
Intellectual / cognitive	Acquired Brain Injury (ABI)	<ul style="list-style-type: none"> <li>• Accessing clinic</li> <li>• Understanding written and verbal COVID-19 health advice</li> <li>• Communicating with healthcare workers</li> <li>• Achieving adequate nasal swab specimen</li> <li>• Informed consent</li> <li>• Behaviours of concern</li> </ul>
	Intellectual impairment including Down syndrome	<ul style="list-style-type: none"> <li>• Accessing clinic</li> <li>• Understanding written and verbal COVID-19 health advice</li> <li>• Communicating with healthcare workers</li> <li>• Informed consent</li> <li>• Anxiety - of new situations or people</li> </ul>
Autism	Autism spectrum disorder (ASD)	<ul style="list-style-type: none"> <li>• Accessing clinic</li> <li>• Understanding written and verbal COVID-19 health advice</li> <li>• Communicating with healthcare workers</li> <li>• Achieving adequate nasal swab specimen</li> <li>• Behaviours of concern</li> <li>• Anxiety - of new situations or people</li> </ul>

## Appendix 2: Alternative COVID-19 testing options for people with disability

The table below provides various options for testing services that could be used as an alternative to the standard nose and throat swab. The type of testing service utilised will depend on the individual circumstances of the person with disability. These testing options should be discussed and decided in collaboration with the person with disability, their personal support team including their GP, service provider, the local public health unit and, if necessary, the Public Health Response Branch.

Testing service	Description of process	Advantages	Disadvantages
Home testing	<p><b>By health professional</b></p> <ul style="list-style-type: none"> <li>Client/carer contacts GP with request and a referral is made for home test by health professional</li> <li>Testing service provider (health professional) attends client home, takes swab and delivers specimen to lab</li> <li>Testing service provider delivers specimen to lab</li> <li>Options: service is delivered through private pathology providers or augmenting the HITH model</li> </ul> <p><b>By trusted carer</b></p> <ul style="list-style-type: none"> <li>Client/carer contacts GP with request and a referral is made for home test by trusted carer</li> <li>Testing service provider attends client home, trusted carer takes swab under supervision of service provider, alternatively, trusted carer is provided instruction to take swab by health professional via telehealth</li> <li>Testing service provider delivers specimen to lab</li> </ul>	<p>Addresses barriers including:</p> <ul style="list-style-type: none"> <li>Travel challenges i.e. due to cost, chronic illness, mobility, unable to travel in COVID-safe manner</li> <li>Disruption to routine</li> <li>Difficulties communicating with unfamiliar health professionals</li> <li>Already established relationship between client and trusted carer may increase likelihood of successfully collecting a swab</li> </ul>	<ul style="list-style-type: none"> <li>Lack of availability in rural and remote areas</li> <li>Healthcare worker safety concerns</li> <li>Poor specimen quality and increased risk of false negative result due to inexperience if a trusted carer takes the swab</li> <li>Risk of inappropriate pressure for the trusted carer to perform the test</li> <li>If a trusted carer performs the swab, there is a risk this will negatively impact the ongoing relationship with the person with disability and their ongoing needs i.e. through associated trauma</li> <li>Risk of physical injury to the trusted carer if there is negative client reaction</li> <li>Risk of physical injury to the person with disability if the test is improperly carried</li> </ul>

Testing service	Description of process	Advantages	Disadvantages
Supervised specimen collection by trusted carer	<p><b>At GP practice</b></p> <ul style="list-style-type: none"> <li>Client/carer books GP appointment</li> <li>Client and trusted carer attend GP practice</li> <li>Trusted carer takes swab under supervision of GP</li> <li>GP arranges specimen delivery to lab</li> </ul> <p><b>At COVID-19 clinic</b></p> <ul style="list-style-type: none"> <li>Client and trusted carer attend COVID-19 clinic</li> <li>Trusted carer takes swab under supervision of nurse</li> <li>COVID-19 clinic arranges specimen delivery to lab</li> </ul> <p><b>At home</b> See above</p>	<p>Addresses barriers including:</p> <ul style="list-style-type: none"> <li>Difficulties communicating with new health professionals</li> <li>Difficulties successfully collecting swab</li> <li>Reduced risk of poor specimen quality, contamination and risk of transmission due to incorrect donning/doffing of PPE</li> </ul>	<ul style="list-style-type: none"> <li>Is not accessible for people who cannot travel or travel in COVID-safe way</li> <li>May increase the risk of poor specimen quality and false negative result due to inexperience if a trusted carer does not get a successful swab</li> <li>Lengthier appointment times</li> <li>Risk of inappropriate pressure for the trusted carer to perform the test</li> <li>If a trusted carer performs the swab, there is a risk this will negatively impact the ongoing relationship with the person with disability and their ongoing needs i.e. through associated trauma</li> <li>Risk of physical injury to the trusted carer if there is negative client reaction</li> <li>Risk of physical injury to the person with disability if the test is improperly carried</li> </ul>
Less invasive COVID-19 testing approaches (saliva, faecal specimen)	<p>While not recommended due to decreased sensitivity of the specimen (87%), a saliva swab is considered better than no swab.</p> <p>Faecal specimens for diagnostic purposes has not been widely adopted in Australia. Discussion with microbiologist is needed if this is the only option</p>	<ul style="list-style-type: none"> <li>Enables specimen collection and a result for some people where nose and throat swab is not feasible.</li> </ul>	<ul style="list-style-type: none"> <li>Not as sensitive as a nose and throat swab so may result in a false negative result</li> </ul>

Testing service	Description of process	Advantages	Disadvantages
Do not test and manage as presumptive case	<p>Manage as a presumptive case and:</p> <ul style="list-style-type: none"> <li>isolate the person for at least 10 days (refer to the COVID-19 CDNA National Guidelines for Public Health Units<sup>8</sup>)</li> <li>identify close contacts and provide advice (that is, isolate for 14 days)</li> <li>test close contacts (including carers and family)</li> <li>identify casual contacts and provide advice.</li> </ul>	<ul style="list-style-type: none"> <li>Reduces risk of transmission if person is positive</li> <li>Avoids distress and potential injury of testing uncooperative individual</li> </ul>	<ul style="list-style-type: none"> <li>Cannot determine if person is positive or negative</li> <li>Large impost on the lives of many people</li> <li>Potential negative consequences of isolation on client</li> </ul>

8. [COVID-19 CDNA National Guidelines for Public Health Units](#)