



**PEOPLE WITH INTELLECTUAL
DISABILITY AND MENTAL
HEALTH/BEHAVIOURAL
PROBLEMS: GUIDANCE ON
COVID-19 FOR COMMUNITY
SETTINGS**

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INTRODUCTION AND ROLE OF CLDTs

1.1 There are approximately 1.2 million people with an intellectual disability (ID) in the UK. They have comorbid mental health problems at a rate of about 40%, which is substantially higher than the general population. About 21% of them are in [contact with specialist health services](#).

1.2 People with ID living in the community have a higher prevalence of psychiatric morbidity and behavior that challenges. There is a [point prevalence](#) of mental disorders of 40.9%, or 28.3% when excluding challenging behaviours. [Some types of mental disorders](#) including schizophrenia, bipolar disorder, dementia (both in adults with Down syndrome and those without), autism and ADHD are more common in adults with ID than in the general population. Depression and anxiety are perhaps not more common than in the general population, though there is a suggestion that they may be more enduring. About 22.5% have challenging behaviours; 10% have [aggressive behaviour](#) and 5% have [self-injurious behaviour](#).

1.3 People with ID living in the community have an extensive range of physical health vulnerabilities and premature mortality. An updated review is available [here](#).

1.4 This vulnerability becomes more pronounced in the wake of the COVID-19 pandemic.

The risk to this group can be conceptualized as

- a. Physical health: Increased risk of mortality and morbidity due to COVID-19
- b. Mental health: Increased risk of worsening mental health symptoms and behavior that challenges or increased risk of mental illness relapses and behavior that challenges.

(Both of the above categories can be seen as vulnerable groups and is in line with the classification proposed by [NHS England in their March 2020 document](#) *Responding to COVID-19: Mental Health, Learning Disabilities and Autism*. Their proposal was to have 3 provisional vulnerable groups- (i) People whose vulnerability stems from a susceptibility to the virus, perhaps because of age or a chronic respiratory condition, (ii) People whose vulnerability stems from their mental health, such as people with an eating disorder, people with underlying conditions and frail older people, or people

with a learning disability, autism or both who are dependent on carers and
(iii) People whose vulnerability stems from both of the above).

1.5 This guidance provides some pointers for practicing clinicians in CLDTs on addressing these risks and vulnerabilities. It draws on published guidance from a range of national bodies including [Public Health England](#), [NHS England](#), [Royal College of Psychiatrists](#), [Royal College of Psychiatrists – ID faculty](#), [MENCAP](#), [RADIANT](#), [National Autistic Society](#), [Autistica](#), [Challenging Behaviour Foundation](#), [Books beyond Words](#), etc. The guidance from [Public Health England](#) is being updated on a regular basis and the reader is advised to refer to the most updated version in conjunction with this guidance.

1.6 Please note that for people living in the community, physical healthcare comes from the GP and primary care services. The role of CLDTs and psychiatrists providing input to them would be primarily to provide information to primary care on these vulnerabilities and to highlight any inequities of access. When individuals known to our services are admitted to general hospitals during the COVID 19 pandemic, we recommend that wherever possible, the CLDT works closely with those in the general hospital to ensure handover of relevant information and assist in decision making. [This engagement](#) can be through the mental health or intellectual disability liaison teams, where they are available in the general hospital. (See more in next section).

RISK TO PHYSICAL HEALTH

1.7 People with an intellectual disability have premature mortality in comparison to the general population and in 2018/19, [41% of those](#) who died, died due to a respiratory cause. [CIPOLD](#) (Confidential Inquiry into Premature Deaths of People with Learning Disabilities) found that for every one person in the general population who dies from an avoidable cause, 3 people with learning disability die from a condition amenable to good quality care. It is a startling statistic that shows the price of [diagnostic overshadowing](#). An updated review of other physical health vulnerabilities of people with an intellectual disability is available [here](#).

Assessing and categorizing

a. Public Health England has identified two groups that are at risk-

- (i) a group *at risk of severe illness* from COVID-19 who need particularly stringent social distancing measures (Box 1)
- (ii) an extremely vulnerable group who are *at very high risk of severe illness* from COVID-19 who need shielding measures (Box 2).

BOX 1: Group at risk of severe illness from COVID-19 who need particularly stringent social distancing measures

- aged 70 or older (regardless of medical conditions)
- under 70 with an underlying health condition listed below (i.e. anyone instructed to get a flu jab as an adult each year on medical grounds):
- chronic (long-term) respiratory diseases, such as [asthma](#), [chronic obstructive pulmonary disease \(COPD\)](#), emphysema or [bronchitis](#)
- chronic heart disease, such as [heart failure](#)
- [chronic kidney disease](#)
- chronic liver disease, such as [hepatitis](#)
- chronic neurological conditions, such as [Parkinson's disease](#), [motor neurone disease](#), [multiple sclerosis \(MS\)](#), a learning disability or cerebral palsy
- [diabetes](#)
- problems with your spleen – for example, [sickle cell](#) disease or if you have had your spleen removed
- a weakened immune system as the result of conditions such as [HIV and AIDS](#), or medicines such as [steroid tablets](#) or [chemotherapy](#)
- being seriously overweight (a body mass index (BMI) of 40 or above)
- those who are pregnant

Please note that the guidance is intended for use in situations where people are living in their own homes and hence the stringent social distancing measures mentioned need to be adapted for residential home or equivalent settings.

BOX 2: Extremely Vulnerable group at very high risk of severe illness from COVID-19 who need shielding measures

People falling into this extremely vulnerable group include:

1. Solid organ transplant recipients.
2. People with specific cancers:
 - people with cancer who are undergoing active chemotherapy or radical radiotherapy for lung cancer
 - people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment
 - people having immunotherapy or other continuing antibody treatments for cancer
 - people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
 - people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs
3. People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe COPD.
4. People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID, homozygous sickle cell).
5. People on immunosuppression therapies sufficient to significantly increase risk of infection.
6. Women who are pregnant with significant heart disease, congenital or acquired.

Please note that the guidance is intended for use in situations where people are living in their own homes and hence the stringent social distancing measures mentioned need to be adapted for residential home or equivalent settings.

- b. As is clear from Box 1, everyone with a learning (intellectual) disability will be identified as being in the group at '*risk of severe illness from COVID-19*'. The primary care clinician-GP may already know whether the patient has any of the conditions name and put them in the appropriate category..
- c. The CLDT or other secondary care services (e.g.: Psychiatry teams) will have to use their clinical judgment in using a RAG rating for their patients. This is because if they were to use the criterion above, then their entire caseload would be rated red. A recommended option therefore would to be rate everyone with an ID as amber, but reserve red for those with additional pathologies (either as set out in boxes 1 and 2 or other conditions which are equally relevant).

Proactive interventions

- a. Please note that for people living in the community, physical healthcare comes from the GP and primary care services. The role of CLDTs and psychiatrists providing input to them would be primarily to provide information to primary care on these vulnerabilities. They can use their clinical judgment to work with primary care, families, residential care providers and the patient or client to develop the following. It may be particularly relevant for those rated red on the RAG rating.

Hospital passport

- b. Help to prepare a [hospital passport](#). (pay particular attention to the presence of physical problems including dysphagia, sensory deficits, etc).

COVID care plan

- c. Help to prepare a COVID care plan (see Box 3) which will clearly set out the physical health risk factors for the person, the person's functional level, etc.

BOX 3: COVID CARE PLAN for a RAG rating- Red patient:

(This is a representative example and services can adapt as needed)

Patient name, Gender, Date of Birth: AB, male, 01/01/1965

1. Mr AB is a 55-year-old Caucasian male who is in supported living.
2. Diagnosis (mental health): Mild Intellectual Disability, Autistic Spectrum Disorder, Paranoid Schizophrenia
3. Diagnosis (physical health): Bronchial Asthma and early COPD, no hospitalizations for that, not on regular inhalers. He is an ex-smoker who is off cigarettes for over 5 years. He has obesity with a BMI of 31 (He is not morbidly obese).
4. His current medication is Depot Olanzapine xxxxxxx and Tab Procyclidine xxxxxx. He is on PRN salbutamol inhalers that he usually does not like taking.
5. He is in supported living and has 24 hour staff support. At present, though not keen on exercise he has no active physical health symptoms. He carries out his daily activities with little help from others.

Actions- Information shared with GP

1. Mr AB is rated as a high risk/ vulnerable patient (RAG rating: Red). This is firstly because he has a mild learning disability, bronchial asthma and early COPD, all conditions that comes within the category of the group at risk of severe illness from COVID-19. Secondly, he is also considered to be vulnerable to having mental health distress and relapse of his mental illness.
2. The CLDT has given him and the staff in his home the following support
 - a. Mental Health: Medication advice (xxxxxx)
 - b. Mental Health: Updated psychological formulation and behavior support plans
 - c. Advice on a structured timetable of activities
 - d. Advice on social distancing and other COVID related precautions
 - e. Advice on hospital passport which has been completed.
 - f. Advice on communication passport which has been completed.
 - g. Any other issues as relevant from para 2.3- d of this guidance
 - h. He appears to have the capacity to understand this information. His capacity with regard to treatment decisions, should he become physically unwell will need to be taken by the treating clinician at that time.
 - i. For any additional information from the CLDT, contact xxxxxxxxxxxxxxxxxxx

- d. The COVID care plan and/or hospital passport could cover, as needed, issues of diagnostic overshadowing, listening to parents or carers, need for reasonable adjustments, communication, behavioural responses to illness, capacity, specialist mental health support that is available, any end of life or do not attempt cardio-pulmonary resuscitation (DNACPR) discussions that may have happened, as appropriate, etc.

- e. [Explain to patients and families](#), the precautions around hand washing, the need not to touch their face or eyes as far as possible, the use of tissues while coughing or sneezing and the need to dispose the tissues, the unit's new protocols about restrictions on visits, the limitations on community leave, precautions adopted in areas where people used to congregate before (eg: dining rooms, activity rooms, etc.), the processes that will be followed in the event of a suspected case and the need for isolation if there is a suspected case (an ID adapted education package). There are a number of new resources available for these discussions, including one from [Books beyond Words](#).
- f. In case of patients deemed not to have the capacity to understand this, have best interest discussions on the procedure that will be followed if isolation is needed. Use technology (e.g.: Skype or equivalent) to facilitate these discussions with carers and families. Please be aware of any LPA (Lasting Power of Attorney) for health and welfare or Court of Protection appointed deputy.
- g. Emphasise the need to monitor for [signs and symptoms of COVID-19](#) - fever, new cough and [other features](#).

Client's community contact:

- The [stringent social distancing](#) should, in theory, apply to all those with an intellectual disability because they are at risk of severe illness. For those with intellectual disability and additional conditions that bring them in the extremely vulnerable group at very high risk of severe illness, [shielding measures](#) should apply, in theory too. This guidance is intended for use in situations where people are 'living in their own homes'. For those in residential settings, there are [separate guidelines](#).
- Avoiding contact with anyone who is showing suspected symptoms, avoiding social contact with others including family or friends, avoiding use of public transport, etc are reasonable steps. Those supporting the client can use [accessible information sources](#) and explain this to the patient or client group.
- In rare circumstances, there may be a need to consider exceptions. The relevant legislation provides the general prohibition that during the emergency period "no person may leave the place where they are living without reasonable excuse". It however provides that it is a reasonable excuse to "avoid injury or illness or to escape the risk of

harm". For some people who are rigidly routine bound and prone to extreme outbursts of aggression or self injury when those are changed, there may be a case to have some community trips as a way to escape the risk of harm. This should be an exception rather than the rule and the treating team may need to discuss this carefully with the family and carers. This may change further as government guidance changes. The GP/ CLDT/ psychiatrist, etc. can be involved in these decisions.

Community visits to the client and outpatient appointments

- As far as possible, use smart technology- telephone appointments, Skype and other equivalents.
- If a community visit is necessary, enquire beforehand whether the client or anyone else in the household is having any symptoms suggestive of a COVID infection.
- If yes, look at alternatives to the visit.
- If a visit is deemed absolutely necessary based on risk assessments, then go ahead with it.
- Current guidance in some organisations, though not all, is that the assessing clinician should wear personal protective equipment (PPE) for all face to face interactions with patients regardless of whether the patient has symptoms of COVID or not. Guidance on this changes frequently and please refer to the Public Health England website for the latest information. At present, as a minimum, this should be a fluid resistant surgical mask, single use disposable apron, gloves and eye protection if blood and or body fluid contamination to the eyes or face is anticipated. A video from Public Health England that shows the donning and doffing procedure is available [here](#).
- It is unlikely that there will be any aerosol generating procedures (AGP) on such assessments. (It has been clarified that spitting is not such an AGP. Trust guidance on spitting is due to be published soon). If a patient meeting the case definition undergoes an aerosol generating procedure (AGP), then a FFP3 respirator, long-sleeved disposable fluid-repellent gown, gloves and eye protection must be worn; in practice, in a psychiatry ward this scenario may arise in a cardio-pulmonary resuscitation attempt and/or use of suction. Use of CPAP and use of high flow nasal oxygen are also noted as aerosol generating procedures.

End of Life and DNACPR discussions

- There is a justifiable anxiety in many quarters that if the COVID-19 pandemic gets worse, people with intellectual and other developmental disabilities will be denied access to the physical healthcare that they deserve.
- It is an anxiety which was worsened when the NICE rapid guidelines on access to critical care suggested the use of the Clinical Frailty Score (CFS), an instrument that would have systematically disadvantaged people with an intellectual disability. To its credit, [NICE quickly amended the guidelines](#) to make clear that CFS should not be applied to this group.
- Their disability notwithstanding, the vast majority of people with intellectual disability known to CLDTs lead full and fulfilling lives. Hence, the issue of end of life or DNACPR is not particularly relevant for them but may arise.
- There is however a small group of people who are an ageing population with multiple frailties who have suffered a marked deterioration in their adaptive functioning. Likewise, there may be a further group who while relatively healthy now, have a precipitous decline in their physical health once they develop a virulent infection. In the context of COVID-19 or other acute illnesses, there may be a need to consider carefully formulated plans for these groups.
- The role of the CLDT is not necessarily to be in charge of creating those plans, but work closely with the client, the family, carers and primary care in facilitating these discussions as appropriate.
- The [underlying principles](#) for any such discussion as set out in the document *'The route to success in end of life care - achieving quality for people with learning disabilities'* are care being client-centred and integrated, individuals being treated with dignity and respect, people's preferences being identified and respected and care being provided after death. Processes that create personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices have also been described by the [Resuscitation Council](#) in their document *Respect*. Wherever appropriate, treating teams should use the guidance from these

documents to formulate these plans. More guidance on this is expected in the next few days.

RISK TO MENTAL HEALTH

1.8 As set out earlier in paragraphs 1.3 and 1.4, people with an intellectual disability have [considerable psychiatric co-morbidity](#).

1.9 It is perhaps entirely predictable that when faced with an actual or suspected COVID-19 infection and the inevitable restrictions on their activities that it brings, there may be an increased risk of worsening mental health symptoms or mental illness relapses and behavior that challenge.

Assessing and categorizing

1.10 The CLDT or other secondary care services (eg: Psychiatry teams) will have to use their clinical judgment in using a RAG rating for their patients. A recommended option therefore would be to rate everyone with an ID and an additional mental health diagnosis as amber, but reserve red for those with either multiple diagnoses *or* a severe intensity of a single diagnosis *or* on medication that needs close monitoring (eg: Clozapine).

Proactive interventions

- a. These should run in conjunction with the proactive interventions set out for the risk to physical health.
- b. [Explain to patients and families](#), the precautions around hand washing, the need not to touch their face or eyes as far as possible, the use of tissues while coughing or sneezing and the need to dispose the tissues, the home's new protocols about restrictions on visits, [the processes](#) that will be followed in the event of a suspected case and the need for isolation if there is a suspected case (an ID adapted education package). There are a number of new resources available for these discussions, including one from [Books Beyond Words](#).
- c. In case of patients deemed not to have the capacity to understand this in spite of all these efforts, have best interest discussions on the procedure that will be followed if

isolation is needed. Use technology (eg: Skype or equivalent) to facilitate these discussions with carers and families.

- d. Have a range of activities which are shorter duration and deliverable within the hospital ward or units. [A range](#) of [resources](#) and [suggestions](#) are [available](#) for [this](#) from [various](#) agencies.
- e. Be aware of the following factors that may cause [emotional distress](#):
 - Changes in routine causing increased anxiety, agitation and acting out behaviours. This can be related to difficulties with communication and understanding the changes, as well as mental health problems, and other associated functions (e.g. demand avoidance, or access to tangibles, including previously enjoyed activities).
 - A change in key staff members – the patient’s usual keyworker, named nurse, doctor, therapist may be self-isolating or unwell causing rising anxiety levels and disruption
 - The introduction of PPE for all face to face interactions may impact in three ways. Firstly the face mask will hide important facial expressions which our service users need to assist understanding. Secondly, the mask could also impact on the intelligibility of our speech. Thirdly, the use of PPE could frighten some service users which could lead to a flight/fright response. During these times people are less likely to pick up on communication from others, particularly related to emotions. The following advice may help the interactions between staff and service users.
 - Introduce yourself each time you see someone. Use of the staff boards is particularly useful at these times.
 - Slow speech down, and increase volume slightly. Try not to shout as this can distort the message
 - Say the person’s name before speaking to them. There may not be the visual cues to help them understand you are directing the message to them.
 - Keep information very clear and concise – think one piece of information per sentence

- Allow the person time to process what you have said
 - Be positive in your communication – tell the person what you would like them to do.
 - Your facial expression is limited – try to make your eyes warm and caring as this is the only thing people can properly see
 - Use other means to support your message – use natural gesture, write it down, draw it out so the person can see what you are talking about.
 - Check back with the person you have a shared understanding. Avoid using ‘do you understand?’ as people will respond positively. Ask ‘what is our plan?’ ‘what have we agreed?’
 - Be aware that some service users already struggle with asking for help. This difficulty may increase with the use of PPE. Observe carefully for any changes which could suggest a need for assistance.
- f. Do not assume that distress and acting out behaviours are necessarily a relapse of mental illness. Incorporate these and other COVID related mental health risks into the formulation and Behaviour Support Plan which should directly inform psychological and other interventions.
- g. Review the psychotropic medication regime and ensure that it is in line with the Royal College of Psychiatrists [good practice guidelines](#) and [NICE guidelines](#). In particular, pay attention to the possibility of side effects like respiratory depression and cardiac effects. This may mean a careful analysis of effects and side effects and a considered view about use of psychotropics to maintain good mental health. Also be aware of diagnostic overshadowing- (e.g.: a high fever may well not be due to COVID 19, but related to the rare side effect- Neuroleptic Malignant Syndrome or Serotonin Syndrome).
- h. Ensure close liaison with pharmacy services to ensure that any prescribed psychotropic medication is available. FP10 prescriptions can be posted via the royal mail tracked service to the service users preferred chemist and emailed on nhs net.
- i. Identify patients on depot medication and consider increasing dose duration as a proactive measure if suitable clinically. Treating teams should be aware where the depot is

administered. (e.g.: GP/ at inpatient units/ by the community nurse from the CLDT, by the CMHTs etc.).

- j. Carefully monitor behavior, mental state and the use of any restrictive interventions in the home setting.
- k. Try and minimize the risk of in-patient psychiatric ward admission as far as possible. To liaise and flag up to service commissioners, instances where service users are at a risk of placement breakdown. In keeping with good practice, continue to have Care and Treatment Reviews (CTRs) that can be held with aid of technology.
- l. Work in conjunction with family members and carers to allay patient anxieties. Encourage alternatives to face to face visits- e.g.: telephone calls, use of Skype, etc. so as to maintain contact.
- m. Treating teams to start considering offering training to community service providers (e.g.: on topics like epilepsy, dementia etc.) using technology, given that face to face training is unlikely to restart for some time.
- n. Pay attention to sources that offer information on [minimizing health anxiety](#) among [service users](#), carers and professionals.

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