

CONSIDERATIONS WHEN OFFERING MENTAL HEALTH FIRST AID TO A PERSON WITH AN INTELLECTUAL DISABILITY

These guidelines are for adults offering mental health first aid to adults and adolescents with an intellectual disability. The role of the first aider is to assist the person until appropriate professional help is received or the crisis resolves. These guidelines are a general set of recommendations. Each individual is unique and it is important to tailor your support to that person's needs and abilities. These guidelines have been developed as part of a suite of guidelines about how to best assist a person with mental health problems. The guidelines should be used in conjunction with existing mental health first aid guidelines that are available on the MHFA Australia website (mhfa.com.au).

Some people with an intellectual disability may have limited or no functional speech. People with intellectual disabilities who have complex communication needs may use augmentative or alternative communication strategies, including communication partners, to support their communication. Communication accessibility is critical for effectively offering mental health first aid. In these guidelines, when we make statements such as "talk to the person" or "ask the person", this is to be done based on their communication preferences. And therefore, may mean using communication aids (e.g. communication boards and books) or communicating with them via a support person. For more information see the section on communicating with the person.

KNOWING ABOUT INTELLECTUAL DISABILITY AND MENTAL HEALTH PROBLEMS.

*A **mental health problem** is when there is a major change in a person's normal way of thinking, feeling or behaving. It affects the person's ability to get on with life. It does not go away quickly or lasts longer than normal emotions or reactions would be expected to. It might involve a diagnosed mental illness, a worsening of mental health or an undiagnosed problem, or a drug or alcohol problem.*

People with an intellectual disability experience impaired mental functioning and reduced ability to manage daily life, such as communication, social participation and independent living across multiple environments such as home, school work and community.¹ These impairments are present before the age of 18. Intellectual disability can be mild, moderate, severe or profound (see box). When offering mental health first aid, it is important not to make assumptions as to the cognitive ability of the person.

People with an intellectual disability are more likely to experience mental health problems than the general population and the likelihood of developing a mental health problem is higher in people with a more severe intellectual disability.

People with an intellectual disability, and their families, carers or other support workers may have a limited understanding of mental health problems.

¹ American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.)

LEVELS OF INTELLECTUAL DISABILITY

Mild - The person can live independently with intermittent support needed during transitions or periods of uncertainty.

Moderate - The person may achieve independent living with moderate levels of support, e.g. group homes. Limited support needed daily.

Severe - The person requires extensive daily assistance with self-care and safety.

Profound - The person requires 24-hour care.

Adapted from: American Association on Intellectual Developmental Disabilities and the Diagnostic and Statistical Manual of Mental Disorders. Fifth ed.

HOW DO I KNOW IF A PERSON WITH AN INTELLECTUAL DISABILITY MAY BE EXPERIENCING MENTAL HEALTH PROBLEMS?

People with an intellectual disability experience mental health problems in the same way that people without an intellectual disability do, however, the symptoms may present differently. Therefore, it is important to know the signs and symptoms of mental health problems in people with an intellectual disability (see box).

If you notice changes in the person's behaviour you should consider a mental health problem as a possible reason, and not dismiss these changes as part of the person's intellectual disability. Do not assume that any one change in the person indicates a mental health problem, rather consider the frequency and severity of the changes. If you do not know the person well and are not sure if the signs or symptoms you have noticed are unusual for them, consult others who provide them support (e.g. colleagues, carers or family), with appropriate consent (e.g. from the person or their legal guardian²).

If you are a disability worker or paid carer

If the person is not experiencing a mental health crisis (e.g. risk of harm to themselves or others) you should talk to an appropriate work colleague (e.g. someone who has spent time with the person, a manager or supervisor, or a case manager) to see if anyone else has noticed similar changes in the person's behaviour or mood. If you are required by your employer to record information about any changes in the person's behaviour or mood, do this in a factual way rather than giving an opinion.

² Some people with an intellectual disability have an appointed legal guardian. A legal guardian is a person who has been given the legal power to make important decisions on behalf of the person, e.g. what care and services the person should have.

RECOGNISING MENTAL HEALTH PROBLEMS IN A PERSON WITH AN INTELLECTUAL DISABILITY

Any major change in the person's thoughts, feelings or behaviour, which impacts on their daily functioning and that is persistent or worsens over time could indicate a mental health problem. Other signs that may indicate a mental health problem in a person with an intellectual disability include:

- Physical complaints, e.g. headaches, weight loss or gain, pain
- Decreased or increased body movement
- Doing things instead of going to bed, waking a lot, or resists going to bed
- Apparent decrease in skills
- Changes to speech, e.g. more talkative or louder than usual, asking repeated questions or speaking quickly
- Changing quickly between activities
- Increased difficulties completing tasks
- Onset or increased self-injury, e.g. hitting one-self, pulling out hair
- Appearing fearful or uncharacteristically suspicious, e.g. of familiar carers or family members
- Anger or agitation, e.g. disruptive behaviours such as shouting, swearing, screaming, lashing out at others
- Being unwilling to take part in their normal activities or participating but not appearing to enjoy them
- Being unwilling to eat meals, throwing them away or spitting out the food
- Seeking excessive reassurance that they are doing well or that they are a good person
- Obsessive behaviours, e.g. arranging, organising, hand washing
- Withdrawing from others
- Seeking more attention
- Acting much more confidently than usual.

Adapted from: www.idhealtheducation.edu.au

INFORMATION ABOUT SPECIFIC MENTAL HEALTH PROBLEMS IN PEOPLE WITH AN INTELLECTUAL DISABILITY

There are guidelines on how to provide mental health first aid when a person is experiencing specific mental health problems. You can find these on the Mental Health First Aid Australia website (mhfa.com.au). The following are additional considerations when providing mental health first aid to a person with an intellectual disability.

Anxiety

Anxiety in people with an intellectual disability is often misdiagnosed as 'challenging behaviour'. For instance, obsessive compulsive disorder is often confused with special interests or unique routines, e.g. someone may be obsessed with a TV character and love to read or hear about them or want to eat from a certain plate. However, it is important to note that special interests and routines, although seemingly 'obsessive' may help the person cope with stress and they should not be encouraged to change these.

Hallucinations or delusions

If the person appears to be experiencing hallucinations or delusions, do not assume that this is the result of a mental health problem, as it may be the actual reality of the person, e.g. they may report that others are staring at them which could be due to their 'different' appearance or they may believe a carer is trying to hurt them if they do not get on with that person. Similarly, if the person thinks they are being controlled by others, do not assume this is a delusion, as people with an intellectual disability may have less control over their lives. If the person is talking to themselves, do not assume they are experiencing hallucinations, as it is not uncommon for people with an intellectual disability to talk to themselves, have a conversation with an imaginary person or inanimate object, repeat conversations or replay arguments they have heard.

If you are concerned that the person may be experiencing psychosis please see the Mental Health First Aid for psychosis guidelines on the Mental Health First Aid Australia website (mhfa.com.au).

Eating disorders

Although some disordered eating may be related to the person's disability, do not dismiss signs of a potential eating disorder as eating rituals related to the person's intellectual disability.

There are certain conditions and medications that may affect the person's eating habits. Therefore, if you notice changes in the person's eating habits encourage them to seek medical advice.

Substance use

If the person appears to be incoherent, physically unsteady, confused, disoriented or frightened, do not assume that they have been using alcohol or other drugs, as there may be other reasons for this that require medical attention. If the person has been using alcohol or other drugs, do not dismiss this as understandable in their circumstances, e.g. people may think "I would drink too if I were them."

Be aware that the person may have difficulty understanding the consequences of their substance use.

Dementia

If you are concerned that the person may be experiencing confusion related to dementia and you are concerned for the person's safety, raise your concerns with the person's carer or support person.

COMMUNICATING WITH THE PERSON

Learn how an intellectual disability may impact communication and comprehension. Do not make assumptions about the person's communication, rather try to find out as much as possible about their communication style and preference. Determine if the person has a document that explains their communication preferences (e.g. communication passport) and seek advice from someone who knows the person well about the best way to communicate with them.

People with an intellectual disability may use a range of communication methods (e.g. they may rely more on non-verbal communication or communication aids) or may need assistance to express themselves verbally. Try to use any communication aids that the person uses.

Enhancing comprehension

It is important to be flexible in your communication style with the person. Frequent breaks or multiple short sessions might be required to enhance comprehension and communication. Do not assume the person cannot understand you or that their ability to express themselves is an indication of how much they understand.

The following tips may be helpful in enhancing good communication:

- Give the person time to think about what has been said or to express themselves.
- Use simple, short statements or questions.
- Use descriptive rather than technical language.
- Do not use abbreviations when communicating with the person, e.g. "CBT".
- Do not use metaphors, sarcasm or idioms, e.g. "under the weather".
- Do not try to finish the person's sentences.
- Do not provide the person with too many options as this may be confusing.

- Reinforce important messages to increase the likelihood the person will understand and remember.
- If you need to ask when something occurred, or how long something has been happening and the person struggles to explain in terms of dates, times, hours or weeks, ask in a way that makes it meaningful for them, e.g. "Have you felt this way since before your birthday, or after?" or "Was that at dinner time or breakfast time?"

If you ask the person a question that offers a choice of answers, be aware that they might choose the last option and you should therefore check this by asking the question again later in a different way. Avoid asking the person leading questions (e.g. "You're feeling sad aren't you?") as this may influence them to respond with what they think you want to hear or what they think is the 'right' answer.

As people with an intellectual disability may not indicate when they do not understand something, tell the person that it is ok to say if they do not understand, e.g. by saying "I need to make sure I explain it properly, please let me know if I am not clear enough." Do not assume that the person will tell you if they do not understand. If you think the person has lost track of the conversation, ask the person to share back their understanding of what you have said.

Do not pretend to understand the person if you do not. If you are having difficulty understanding the person, ask them if there is anyone they would like to be part of the conversation who could help you to understand.

Engaging others in the conversation

Ask the person if there is anyone they would like to be part of the conversation to support them and make them feel at ease, e.g. a family member or friend. However, be aware that if other people are present, the person may feel pressured and less able to speak openly or make their own decisions. If you believe that the person is feeling pressured or less able to speak openly because someone else is present, meet with the person alone, if this is possible and the person wants to.

If there are other people present, even if the person has chosen to have them present, ensure the person with an intellectual disability is the centre of the conversation at all times by directing all communication to them. If a legal guardian or other person is present and you want to ask them a question, check with the person if this is okay before doing so.

If you need to clarify with a carer or support person what the person has communicated, you should check with the person if the correct information has been relayed.

Talking about emotions and mental health problems

Allow the person to talk about their experiences. Do not assume that the person cannot describe their symptoms of mental health problems. However, be aware that they may describe their emotional symptoms using physical descriptions, e.g. their heart hurts or

they are sad in their stomach.

Seemingly minor changes or incidents can have a significant impact on a person with an intellectual disability. If the person is distressed, try to identify the cause of the distress and make changes where appropriate, e.g. turning off the TV, asking people to be quiet, moving to another location. Ask the person if they have felt this way before, and if so, what they have done in the past that has been helpful.

If the person is using stimming behaviours or other distractions to manage their emotions during a conversation, do not attempt to stop them, unless they are harming themselves or others. (Stimming behaviours, or self-stimulatory behaviours are repeated movements or sounds, touching or moving objects, and other repetitive behaviours that enable to person to cope with stress and manage emotions.)

SUPPORTING THE PERSON

Respecting the person and their rights

Use 'person-first language' when referring to or talking about the person, e.g. "a person with an intellectual disability" rather than "an intellectually disabled person".

Respect the person's autonomy while considering the extent to which they are able to make decisions for themselves. A person with an intellectual disability has as much right to make decisions for themselves as anyone else. Do not assume that you know what is best for the person or the best way of supporting them; be guided by any instruction the person, their carer or their legal guardian may give.

The person's right to privacy should not be waived simply because they have an intellectual disability. Get appropriate consent (i.e. from the person or their legal guardian), before sharing information with, or asking for information from, someone else unless there is risk of harm to the person or others.

Offering support to the person

Do not make assumptions about what kind of support the person may need, rather ask them how they would like to be supported. If you see that the person may need some practical assistance, try to facilitate this support, i.e. provide the support yourself or find an appropriate person to assist. However, before offering specific supports, check what supports are available to the person.

When offering mental health first aid, you should consider the person's capacity to respond and engage with any suggestions or advice, e.g. support services, self-help strategies or information. Capacity includes the person's abilities, their environment and the support available to them. Do not adopt an over-involved or over-protective attitude toward the person.

If you offer to assist the person and the person does not want your help, respect this, unless there is a risk of harm to the person or others.

Assisting the person to use self-help strategies

Ask the person if they have used self-help strategies in the past that they found helpful. If they have and they need support to use them, support them or encourage them to ask others to support them in their use. If you are going to suggest self-help strategies, consider the person's capacity to engage in these strategies. If the person wants to learn to use self-help strategies but needs support to do so, suggest a support service (where available) that offers specialised education programs to assist them to learn these skills. If the person needs additional support, but family and friends are under stress or 'burnt out', assist the person to find this support elsewhere.

DIFFICULTIES YOU MAY ENCOUNTER

Symptoms of a mental health problem can contribute to an increase in behaviours that others find challenging. Behaviours that others find challenging may also indirectly contribute to the person's mental health problems, e.g. these behaviours could lead to increased isolation which can contribute to low mood. If the person is exhibiting behaviours that others find challenging, do not assume that the person is experiencing mental health problems.

Behaviours that others find challenging can have different functions for different people, e.g. pacing may indicate boredom in one person and a mental health problem in another. If the person is exhibiting behaviours that you find challenging, trying to stop or control the behaviour without addressing how the person is feeling is not likely to be successful. Explore the reasons for the behaviour, e.g. ask if they are in pain or hungry, ask if there is something that is bothering them, look for overwhelming environmental factors (such as bright lights).

Aggressive behaviours

If the person is behaving aggressively, you should try to enlist the assistance of someone who knows the person better. If you are a disability worker, be familiar with the person's behaviour support plan.

Sexually inappropriate behaviours

Sexually inappropriate behaviour is sexual behaviour that negatively impacts on others or is outside of legislation. It is characterised by a range of activities that can be persistent, frequent, harmful, or between unwilling or unequal participants, e.g. in age, size or ability.

If the person is exhibiting sexually inappropriate behaviour:

- Redirect the person, e.g. to another activity or to a private area
- Check with the person's carer or professional to see if any strategies have been put in place

Personal boundaries

Some people with an intellectual disability may respond with an unexpected physical response, e.g. hugging or kissing new people. Try to establish appropriate physical boundaries that both you and the person are comfortable with.

IF THE PERSON IS ENGAGING IN SELF-INJURY

People with an intellectual disability may injure themselves for a range of reasons, e.g. to communicate a need such as hunger, to manage distress, or as a result of stimming behaviours. If the person is engaging in stimming behaviour that is not harmful, understand that these can help the person to feel calm and should not be viewed as self-injurious behaviour. Likewise, do not dismiss self-injurious behaviours as stimming or 'challenging behaviour', as these may be motivated by distress, and better described as non-suicidal self-injury. The term 'non-suicidal self-injury' describes a behaviour where a person deliberately or purposefully hurts themselves to manage overwhelming emotions, but does not intend to die as a result.

The person may be self-injuring because they are trying to communicate something or have a particular need (e.g. hunger, physical pain, lack of control over their environment), try to find out what they are trying to communicate or what they need.

If the person is self-injuring, you should seek assistance and refer to the person's behaviour support plan, if there is one in place.

Physical restraint should only be considered as a last resort when there is risk of serious harm.

IF YOU THINK THE PERSON IS EXPERIENCING ABUSE

People with an intellectual disability are at greater risk of abuse and neglect than the general population, and are more likely to experience abuse that is more severe, repeated, and for a longer period of time. They are also more likely than the general population to be abused by a caregiver or someone they know. Try to talk to the person without the presence of others who may influence their ability to speak freely.

The person might not be aware that any abuse they may be experiencing is unacceptable. If you have reason to believe they may be experiencing abuse and are in immediate danger, call the police. You should also contact an appropriate service for advice on how to support the person, e.g. disability abuse and neglect hotline, crisis support service. Seek advice on how to talk to the person as conversations you have with them may contaminate evidence that could be critical to future legal proceedings.

If the person discloses that they have been abused, record the exact facts about what you have been told and have observed, with appropriate consent, e.g. from the person or their legal guardian. If you assist the person to report abuse, link them in with supports that will support them through the process of reporting, e.g. advocates, housing support.

Know the local laws regarding mandatory reporting of abuse.

IF YOU THINK THE PERSON IS EXPERIENCING TRAUMA

People with an intellectual disability are more likely to have experienced trauma than the general population. Events that may seem 'less significant' can be traumatic for a person with an intellectual disability, e.g. repeated rejection, living in situations where they lack control, teasing and name calling, or having extended hospitalisations. It is important to know that just because the person is not avoiding a certain situation, this does not mean it is not traumatic for them as they may not be able to remove themselves from this situation.

ENCOURAGING PROFESSIONAL HELP

People with an intellectual disability are entitled to use the same mental health services as the general population and have the right to accept or refuse professional help.

Be aware of the barriers that may prevent a person with an intellectual disability from seeking professional help and try to find out if the person has any specific barriers in accessing professional help. If possible, try to assist them to overcome these, e.g. accessing transportation.

Because some symptoms of mental health problems may be explained by physical conditions or can be the result of medication side effects, you should encourage the person to seek medical advice.

Keep in mind that there may not be appropriate resources about seeking help from a mental health professional available for people with an intellectual disability. Explain to the person their options for seeking professional help and, if available, let them know about local mental health services that have expertise in intellectual disability. However, be mindful that the person may not want to attend a mental health service that specialises in supporting people with an intellectual disability.

Provide the person with information that may help them to make a decision about seeking professional help (e.g. what is involved in the various options and the benefits of each option) and provide this in a way that supports them to make an informed choice, e.g. that the information is understood and meaningful.

The person may not be used to having a choice, so it is important to let them know that they can make their own decisions about seeking professional help and can change their mind at any time.

If the person has a legal guardian, involve them with regards to seeking professional help.

Supporting the person to seek professional help

If the person needs support to access professional help, you should ask them if there is someone they know well and trust who they would like to support them. If appropriate to the relationship, support the person to make an appointment with a health professional. If challenges arise that prevent the person from receiving appropriate professional help, try to find an advocate who can support them to access appropriate help.

Supporting the person who has an appointment

Support the person to anticipate the upcoming appointment by explaining what to expect, and making sure they know the time, place and who they will see. If the person thinks they are in trouble because they are going to see a professional, reassure them that they are not.

If you are supporting the person to attend the appointment, you should:

- Let the health professional know if the person has any specific fears or needs that may affect the appointment, with appropriate consent from the person or their legal guardian.
- Encourage the person to take any book or document explaining their communication needs, if they have this.
- Explain to the health professional the person's communication style and preferences, with appropriate consent from the person or their legal guardian.

If you accompany the person to an appointment and the professional is having difficulty understanding the person, you should assist, with the person's permission.

WHAT TO DO IN A CRISIS SITUATION

In a crisis situation, if it is safe to do so, check if the person is wearing a medical alert bracelet or pendant, or has a medical alert tattoo. You should also ask the person if there are certain objects or activities that they find comforting and might help them maintain calm.

SUICIDE

The person may not understand the term "suicide" and you may need to use words such as "kill yourself" or "make yourself die" instead. If you are concerned that the person may be suicidal and the person has a carer or support person with them, share your concerns with them and ask if they are also concerned the person may be at risk of suicide

Calling the mental health crisis team or emergency services

If you call a mental health crisis team, describe the person's symptoms and behaviour and let them know the person has an intellectual disability. If the person has a legal

guardian, let them know what has happened if possible. Try to meet emergency staff on arrival to remind them that the person has an intellectual disability before they approach the person.

If police attend, you should:

- Reassure the person that they are not in trouble, if this is the case
- Tell them that the person has an intellectual disability and appears to be experiencing a mental health crisis and requires medical help
- If the person has a legal guardian, let them know what has happened, if possible.

If police need to be involved due to illegal behaviours (e.g. aggression, sexually inappropriate behaviour), support the person to seek an advocate to assist them.

If the mental health crisis team or emergency services refuse to intervene and you feel the person needs their assistance, strongly advocate for this on the person's behalf.

IF THE PERSON NEEDS TO BE TAKEN TO HOSPITAL

The hospital can be particularly stressful for a person with an intellectual disability, due to factors such as noise, unfamiliar faces, worries about their health or being in trouble, or having difficulty understanding what is happening around them.

If the person needs to be taken or transported to hospital, you should:

- Try to ensure the person has a support person or carer accompanying them, where possible.
- Find out if the person has any documentation or individual requirements that might be helpful (e.g. hospital passport, communication guidelines, etc.) and try to ensure these are made known to hospital staff.
- Explain to the person what is likely to happen.
- If the person has previously had a negative experience with the emergency department, inform the emergency responders of this.

If you accompany the person to hospital, you should provide support until the person sees a health professional or a family member or carer arrives, e.g. request a quiet area to wait, ensure the person's basic needs are met.

PURPOSE OF THESE GUIDELINES

These guidelines describe how members of the public should tailor their approach when providing mental health first aid to a person with an intellectual disability who may be developing a mental health problem, experiencing a worsening of an existing mental health problem or in a mental health crisis. The role of the mental health first aider is to assist the person until appropriate professional help is received or the crisis resolves.

DEVELOPMENT OF THESE GUIDELINES

These guidelines are based on the expert opinions of people with lived experience of psychosis (consumers and carers) and mental health professionals (clinicians, researchers and educators) who are from Australia, Canada, Germany, Ireland, The Netherlands, New Zealand, Sweden, Switzerland, United Kingdom and the United States of America.

HOW TO USE THESE GUIDELINES

It is important to tailor your support to the needs of the person you are helping. These guidelines are a general set of recommendations only, and most suitable for providing mental health first aid in high-income countries with developed health systems.

These guidelines have been developed as part of a suite of guidelines about how to best assist a person with mental health problems. These other guidelines can be downloaded from:

mhfa.com.au/resources/mental-health-first-aid-guidelines

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Enquiries should be sent to: mhfa@mhfa.com.au