INTELLECTUAL DISABILITY MENTAL HEALTH FIRST AID MANUAL

2nd Edition

MENTAL HEALTH FIRST AID

Intellectual Disability
Mental Health First Aid Manual

Second Edition
2010

Adapted by
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with the kind permission of the authors:
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NSW GOVERNMENT Human Services
Ageing, Disability & Home Care

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Text about intellectual disability

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About This Manual

How this manual came about
The 1st edition Intellectual Disability Version of the Mental Health First Aid Manual was developed in 2008 as a result of 2 major factors.

The first was the attendance of some staff from the State-wide Behaviour Intervention Service (SBIS), at an Adult Mental Health First Aid Training Course. SBIS is a service within the Office of the Senior Practitioner, NSW Department of Ageing Disability and Homecare (OSP ADHC).

During the course and after completion the staff felt that those working in the field of intellectual disability could benefit significantly if the content of the manual was adapted for intellectual disability.

The second was the increase in clients with a mild intellectual disability and mental health problems being referred to SBIS and the accompanying requests for simple strategies that direct care staff could use to support those clients they were working with.

Ruth Pappas and Michelle Henwood then approached the authors of the Mental Health First Aid manual to discuss how they could make this happen. Many thanks to both Betty Kitchener and Tony Jorm for their permission and support.

Who is the intellectual disability version of the MHFA manual for?
This manual is for people working in human services who are aware of the standard Mental Health First Aid course and those working in or associated with disability services.

The purpose of this manual is to provide guidance on how to support people with an intellectual disability who are experiencing difficulties associated with mental health problems. There is also information in the manual that will help those with little or no experience interacting with someone who has an intellectual disability.

This manual builds on the information given in the Mental Health First Aid Manual, specifically taking into account the difficulties and needs of the person with an intellectual disability. It thereby makes the Mental Health First Aid approach available to those who work with and encounter a person with intellectual disability.

2nd Edition Intellectual Disability Mental Health First Aid Manual
In early 2010, a 2nd edition of the standard Mental Health First Aid Manual was published with a number of improvements over the 1st edition. The major improvement is that the first aid information is based on Mental Health First Aid Guidelines which were developed by the MHFA Training and Research Program between 2005-2009. These guidelines were developed using the consensus of expert panels of mental health consumers, carers and professionals from developed English-speaking countries. Further details of the guidelines and their development can be found at: www.mhfa.com.au/Guidelines/shtml. This 2nd edition manual also contains updated statistical information on the mental health problems in Australia and incorporated the latest evidence on treatments and services available.
This 2nd edition Intellectual Disability Mental Health First Aid manual has been written in order to ensure it is in line with the 2nd edition standard Mental Health First Aid manual, as well as to incorporate some minor additions to the intellectual disability content.
The demand for the first edition of this ID MHFA manual far exceeded our expectations. Feedback we have received has been extremely positive and has come from all over Australia. The authors continue to welcome feedback from people using the manual.

Mental Health First Aid Website
Up to date information about the Mental Health First Aid Training and Research Program can be found at the above website. This includes a free download of the 1st edition Intellectual Disability MHFA manual from www.mhfa.com.au/downloads.shtml

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The Bridge

1.1 Mental Health Problems & Intellectual Disability in Australia

What is mental health?

There are different ways of defining the term *mental health*. Some definitions emphasise positive psychological well-being whereas others see it as the absence of mental health problems.

For example, the World Health Organization has defined mental health as:

"… a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community." [1]

In this Mental Health First Aid Manual, **mental health** is seen as a continuum, ranging from having good mental health to having mental illness. A person will vary in their position along this continuum at different points in their life. A person with good mental health will feel in control of their emotions, have good cognitive functioning and positive interactions with people around them. This state allows a person to perform well at work, in their studies and in family and other social relationships.

What are mental health problems?

A variety of terms are used to describe mental health problems: mental illness, serious emotional disorder, extreme emotional distress, psychiatric illness, mental illness, nervous exhaustion, mental breakdown, nervous breakdown and burnout. Slang terms include crazy, psycho, mad, loony, nuts, cracked up and wacko. These terms promote stigmatising attitudes and should not be used.

These terms do not give much information about what the person is really experiencing.
A mental disorder or **mental illness** is a diagnosable illness[2] that affects a person's thinking, emotional state and behaviour, and disrupts the person's ability to work and carry out other daily activities and engage in satisfying personal relationships.

There are different types of mental illnesses some of which are common, such as depression and anxiety disorders, and some which are not so common, such as schizophrenia and bipolar disorder. However, mental illnesses, as with any health problem, cause disability, which is sometimes severe. This is not always well understood by people who have never experienced a mental illness.

A **mental health problem** is a broader term including both mental illnesses and symptoms of mental illnesses that may not be severe enough to warrant a diagnosis of a mental illness.

This manual provides information on how to assist people with mental health problems and not only those with diagnosable mental illnesses. There are so many different types of mental health problems that it is not possible to cover them all in this manual. The most common and the most severe problems are covered. However, it is important to note that the mental health first aid principles in this manual can be usefully applied to other mental health problems.

What is intellectual disability?

Intellectual disability (also referred to as mental retardation, developmental disability) is a condition which shows itself as limitations in the person's ability to learn about and solve the problems of daily life and to be independent in the activities required for daily living.

Intellectual disability occurs along a spectrum and is present in some form in about 3% of the population. It is often present from a person's early years of life and generally speaking is permanent.

How does intellectual disability affect a person?

Intellectual disability affects many aspects of the person's day to day life.
People with an intellectual disability usually have some difficulty:

- communicating
- remembering things
- understanding social rules
- understanding cause and effect for everyday events
- solving problems and thinking logically
- reacting and interacting in ways that are characteristic for their age.

Recognising people with an intellectual disability

It is not always obvious that someone has an intellectual disability. Sometimes they are recognisable due to physical characteristics of a particular syndrome such as Down Syndrome, but this is not always the case. The following box gives areas that you could ask the person about to help identify whether they have an intellectual disability.

Possible indicators of an intellectual disability		
Activities	**Remember**	**Life Experience**
Can they: • read • write • manage money • look after their personal care • tell the time • cook • communicate clearly with other people?	Can they remember: • significant things about themselves (e.g. birthday) • significant things about their environment (e.g. where they live) • when to do things (get up, what time dinner is) • what you have said?	Have/do they: • attend a special school or class within a mainstream school • attend a day centre • live(d) in an institution or intellectual disability service • have people who support them (e.g. care worker, advocate etc) • manage in social situations?

Adapted from: Hardy S., Chaplin E.[9]

How common are mental illnesses?

Mental illnesses are common in the Australian community. The 2007 National Survey of Mental Health and Wellbeing, a community survey of 8,841 people aged 16-85 years of age, living in private dwellings across Australia, found that one in five (20%) had a common mental illness (depressive, anxiety and/or substance use disorder) at some time during the 12 months before the survey.[3] (see table below) This means that one in five Australians aged between 16-85 suffer from some form of common mental illness in any year. This is equal to 3.2 million people.

Percentage of Australians aged 16-85 with common mental illnesses in any one year[3]

Type of mental illness	Males	Females	All
Anxiety disorders	10.8%	17.9%	**14.4%**
Depressive disorders	5.3%	7.1%	6.2%
Substance use disorders	7.0%	3.3%	**5.1%**
Any common mental illness	**17.6%**	**22.3%**	**20.0%**

These results reflect the whole population of Australia aged 16-85 years. Research on specific sub-groups within the population may show higher or lower rates of common mental illnesses. For example, Aboriginal people are at a higher risk of anxiety and depression.[4] These three types of mental illnesses often occur in combination. For example, it is not unusual for a person with an anxiety disorder to also develop depression, or for a person who is depressed to misuse alcohol or other drugs, perhaps in an effort to self-medicate. Terms used to describe having more than one mental illness are *dual diagnosis, comorbidity* and *co-occurrence*. Of the 20% of Australians with any mental illness in any one year, 11.5% have one disorder and 8.5% have two or more disorders.[3]

The 2007 National Survey of Mental Health and Wellbeing did not cover less common but more serious mental illnesses. Other research has found that 0.4-0.7% of Australian adults have a psychiatric disorder, such as schizophrenia, in any one year.[5]

Many people with common mental illnesses do not seek any professional help. The national survey found that professional help is received by only 35% of people who have a common mental illness in the past year (59% of people with depressive disorders, 38% with anxiety disorders and 24% with substance use disorders).[6] People with the less common mental illnesses, such as schizophrenia and bipolar disorder, will generally get professional help eventually. However, it can sometimes take years before they are correctly diagnosed and receive effective treatment.[7]

Prevalence of mental health problems in intellectual disability

People with an intellectual disability suffer from the same types of mental health problems as those without such disabilities. Prevalence rates of mental health problems are generally higher for people with intellectual disability than for the general population, suggesting that they are a particularly vulnerable group.[8-10]
Some disorders may be more or less likely and may also present in a different way than in the general population. Prevalence rates for people

with intellectual disability and mental health problems have been placed between 10% and 74%[8-10]. This large variation is a result of the different ways studies have been conducted. In Australia in 2003 according to Australian Bureau of Statistics data 57% of people with an intellectual disability under the age of 65 years also has a 'psychiatric disability.[11]

Difficulties of diagnosis

Assessment of mental illness in those with a mild intellectual disability may be similar to the general population: however there may be greater reliance on others for information.[10]

The presence of intellectual disability poses particular difficulties when it comes to diagnosing a mental illness. There are several reasons for this;[12-14]

- The person with intellectual disability is often unable to express symptoms that a clinician looks for when diagnosing a mental illness
- Mental health workers may attribute all forms of behaviour difficulties to the person's intellectual disability and fail to consider that the behaviours may be a symptom of mental illness
- Unusual or infrequent presentation of symptoms in the intellectually disabled population
- Medications being taken for physical or behavioural issues may mask the presence of mental health symptoms
- Historical information which may deal with previous diagnoses is sometimes inconsistent or missing. This may make it difficult to determine if there has been a change over time.

The relationship between intellectual disability & mental health problems

In the past, the difference between intellectual disability and mental illness was not well understood. People with intellectual disability were accommodated in the same institutions as those with serious mental illness. We now understand that the two are quite separate conditions. It is however possible for a person with intellectual disability to have a mental illness as well.
People with intellectual disability (as is true for most of us) can experience emotional crises because of mental health problems or as learned ways of coping with situations they find difficult (challenging behaviour). Challenging behaviour and mental health problems may exist at the same time. Individuals may also continue to display their usual challenging behaviour in addition to other behaviour indicative of a mental illness.[12]

Impact of mental illnesses

Mental illnesses often start in adolescence or early adulthood. In Australia, half of all people who experience mental illness have their first episode by age 18 and three quarters by age 25.[15] When mental illnesses start at this stage in life, they can affect the young person's education, movement into adult occupational roles, forming of key social relationships including marriage, and the formation of health habits such as the use of alcohol or other drugs.

Consequently, mental illnesses can cause disability across a person's lifespan. This is why it is so important to detect problems early and ensure the person is properly treated and supported.

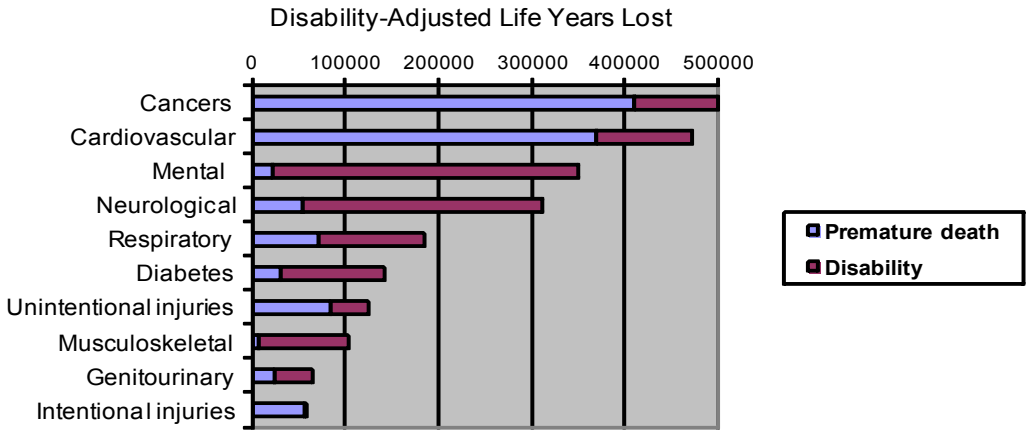
Some illnesses have a major impact by causing premature death while others are major causes of disability. Mental illnesses have their major impact on disability and medical experts rate them amongst the most disabling illnesses.[16] *Disability* refers to the amount of disruption a health problem causes to a person's ability to work, look after themselves and carry on their relationships with family and friends. It helps to understand that the degree of disability which can occur during an episode of mental illness can be comparable to that caused by physical illnesses. Here are some examples:

1. The disability caused by *moderate depression* is similar to the impact from relapsing multiple sclerosis, severe asthma or chronic hepatitis B.
2. The disability from severe *post-traumatic stress disorder* is comparable to the disability from paraplegia.[16]

In recent years has it been recognised that mental illnesses are a major issue for Australia. The Australian Institute of Health and Welfare has concluded that in 2003 mental illnesses ranked as the third biggest source of disease burden in Australia after caners and cardiovascular (heart) disease.[17] *Disease burden* is the combined effect of years lost due to premature death and years lived with disability caused by an illness. While mental illnesses are not major causes of premature death, they are the major cause of disability in Australia.

The graph below shows these two components of disease burden for various categories of illness. Each bar of the graph has two colours: the first shows the portion of disease burden due to premature death and the second the portion due to disability.

Disease burden in Australia, 2003[17]



There is all too often additional suffering caused by attitudes of rejection and stigma towards people with a mental illness. Because the disability caused by mental illnesses may not be readily visible to others, people with mental illness can be judged negatively. They may be incorrectly perceived as being weak, lazy, selfish, uncooperative or not really ill. This lack of understanding contributes to the stigma that people with mental illnesses can experience. The community's attitudes towards mental illness should be fundamentally the same as approaches to physical illnesses.[18] People suffering from mental health problems need the respect and assistance of friends, family members and the broader community.

Factors contributing to mental health problems in people with intellectual disability

It is only recently that there has been recognition that people with intellectual disability can develop the same mental health problems as the general population and that prevalence rates of mental illness are higher for intellectual disability.

As for the general population a combination of biological, psychological and social factors can lead to the development of mental health problems. People with an intellectual disability tend to be more vulnerable to these factors as outlined in the table below.

Factors contributing to mental health problems for people with intellectual disability[19,20,21]

Biological	Psychological	Social
Brain damage Not all people with intellectual disability have brain damage. For those who do, this can cause structural and psychological changes to the way the brain functions, increasing vulnerability.	**Self-worth** Society values achievements such as high social status, independence, employment, relationships and family. People with intellectual disability may have difficulty attaining these, which may affect their self esteem.	**Living in inappropriate environments** People with intellectual disabilities often live in accommodation where they are isolated from their families and community. In such settings they may have little choice and control over their lives. Such environments may provide too little or too much activity or stimulation.
Sensory impairments Sensory impairment can create a barrier to social integration and lead to disablement and problems with self-image.	**Self-image** People with intellectual disability may feel they are different to other people due to either their cognitive or physical disabilities or may feel inferior to others because of their reliance on the support of others. Poor self-image can contribute to mental health problems.	**Exposure to adverse life events** People with intellectual disability are more likely to have been exposed to abuse, trauma, rejection, harassment and exploitation. They are often unaware of or do not understand their rights.

Factors contributing to mental health problems for people with intellectual disability cont.		
Biological	**Psychological**	**Social**
Genetic conditions People with intellectual disability are at a significantly higher risk of mental health problems associated with a number of syndromes e.g. Prader-Willi Syndrome, Rett Syndrome, William's Syndrome, Fragile X Syndrome	**Poor coping mechanisms** People with intellectual disability find it more difficult to plan ahead, consider the consequences of their behaviour or tolerate/manage their frustration and anger. This can result in greater discrimination by others.	**Expectations of others** Low expectations by others of people with intellectual disability can lead to reduced opportunities for participation and the chance to develop skills and confidence.
Medication Side effects of psychotropic medication, particularly when the person is receiving two or more, need to be considered, as these can contribute to mental health problems.	**Bereavement and loss** People with intellectual disability often do not receive the support they require to cope with these stressors. They may not even be told about what has happened. Loss can include siblings leaving home, staff leaving or other clients moving on.	**Family** Some family members can be over-protective, reducing opportunities and leading to over-dependence. Caring for a person with a disability may also put increased pressure on a family leading to increased stress which can affect the family's relationship with the person.
Epilepsy Approximately a third of people with intellectual disability have epilepsy, which for some may be associated with mental health problems. Epilepsy can provoke anxiety in a person, which may lead to them avoiding going out & becoming isolated.	**Difficulty expressing emotions** People with intellectual disability often have trouble expressing their inner thoughts and feelings. They find it difficult to put subtle & abstract emotions into words.	**Reduced social networks** People with intellectual disability often have smaller friendship groups. They may lack the skills required to develop relationships and broaden social networks. Others may develop abusive relationships or mix with inappropriate peers in an attempt to fit in.
	History and expectation of failing. People with intellectual disability are often not given opportunities to achieve, so they develop low expectations. Frequent failure may lead them to develop leaned helplessness, which can lead to a lack of motivation and poor goal setting.	**Economic disadvantage.** Financial and related disadvantages common for people with intellectual disability can contribute to the person's vulnerability to mental health problems.
	Dependence on others The reliance on others by a person with an intellectual disability can lead to overdependence, a lack of self-determination and poor problem solving skills.	**Transitions** Movement between services is often poorly managed. Poor communication between services and bad or no planning adds to the problem. The individual may feel they have little control or influence over what happens to them at this time.
		Discrimination Discrimination by the wider society can leave people with intellectual disability stigmatised and impact on their self-esteem and self-image.
		Legal disadvantage People with intellectual disability may not be aware of their rights & have to rely on others to be advocates for their needs.

Presentation of mental health problems in intellectual disability

- Presentation of mental health problems in people with an intellectual disability will be influenced by factors such as;
- the cause of the intellectual disability
- level of disability and functioning (communication, social and physical)
- personality
- usual behavioural repertoire
- cultural background
- environmental factors.

People with mild intellectual disability and/or sufficient verbal communication will have a similar presentation of symptoms to the general population. Those with a more significant degree of intellectual disability and inadequate verbal communication are more likely to display their mental health problems through changes in behaviour and behaviour problems (challenging behaviour).[22,23]

For convenience, throughout this manual the term "behaviour" is used to describe potential signs and symptoms of a mental health problem, which may include thoughts and feelings.

It may be useful to consider the following if you suspect that a person with intellectual disability may have a co-existing mental health problem.[12,22]

- Is the person behaving in ways that are different to their usual behaviour? e.g. changes to sleeping and eating patterns, posture and movement.
- Are these changes in behaviour occurring across the majority of settings?
- Does the person seem to be experiencing emotional reactions such as anxiety or elation that are out of keeping with the situation?
- Do they talk or interact with someone who is not there or is there anything that suggests that the person is being influenced by unseen forces?
- Has there been a reduction or increase in the person's mood or level of motivation?
- Has there been a reduction or change in the person's abilities (e.g. social, daily living, and work related skills), leisure activities or preferred routines?
- Is the person acting in a way that is dangerous to themselves or others?

There are many possible causes for these and other changes. It is important to first rule out a medical or physical condition which may be triggering the behaviours of concern. Bowel conditions and ear infections are two of the most common physical ailments that may trigger behaviours that can be mistaken for symptoms of a mental health condition.

The task of determining whether a person with an intellectual disability has a mental illness is one for a skilled professional. In doing so he/she would consider:

- the nature of the behaviour /s reported
- recent changes in behaviour
- mood changes
- the person's communication abilities
- any changes in sleep, appetite, weight
- current accommodation, social, educational and vocational environments.

It is vital that where data has been gathered regarding any of the above it is taken to the consultation with the professional. It may take more than one consultation with them for a diagnosis to be made.

Spectrum of interventions for mental health problems

Society has a wide range of interventions for preventing mental health problems and helping people with mental illnesses. Mental health first aid is just one part of the spectrum of intervention. The diagram on the following page illustrates this. It shows the course of a well person developing mental health problems, which may progress on to a diagnosable mental illness, and then to the process of recovering. There are different types of interventions appropriate at these states of mental health. For the person who is well or with some mild symptoms, prevention programs are appropriate. For the person who is moving from mild mental health problems to a mental illness, early intervention approaches can be used. For a person who is very unwell with a mental illness, a range of treatment and support approaches are available, which will assist the person in their recovery process.

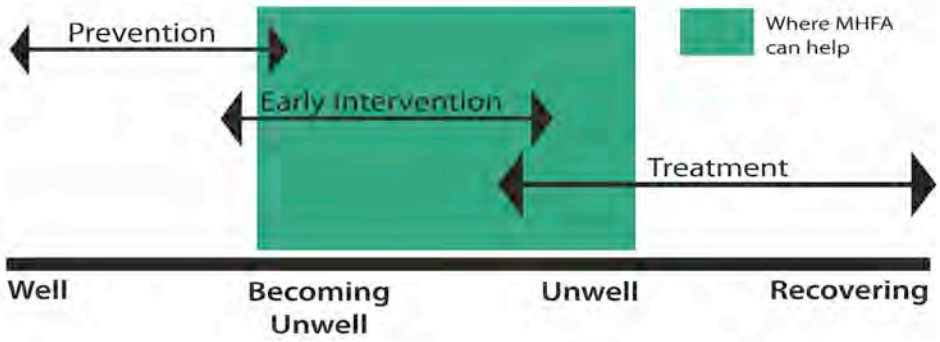
Prevention

Prevention programs are available to help everyone in the community, as well as targeted programs for people who are particularly at risk. These can include campaigns to reduce stigma of mental illnesses, drug education programs in schools, resilience training, stress management courses, and parenting skills training.

Early intervention

Early intervention programs target people with mental health problems and those who are just developing mental illnesses. They aim to prevent problems from becoming more serious and reduce the likelihood of secondary effects such as loss of employment, school drop-out, relationship break-up and drug and alcohol problems. Many people have a long delay between developing a mental illness and receiving appropriate treatment and support. The longer people delay getting help and support, the more difficult their recovery can be.[7]

It is important that people are supported by their family friends and work colleagues during this time. People are more likely to seek help if someone close to them suggests it.[24,25] **It is during this early intervention phase that giving mental health first aid can play an important role.**



Treatment and Supports

There are many different types of treatment and supports that can help with mental illnesses function better and aid their recover. Once the person has made the decision to seek help, they may choose from a number of helping sources, treatment approaches, and service settings. There is no "one size fits all", approach for mental illnesses.

There are a wide range of treatment options available to the general public: however, their availability to people with an intellectual disability may be limited because of:

- Assumptions that people with an intellectual disability aren't able to benefit from the same interventions and treatments
- Lack of awareness about services offered by mental health and other providers of treatment and
- Lack of mental health staff trained and experienced in working with people with an intellectual disability.

Fortunately, there is growing recognition that, within limits, established treatments can be adapted to the circumstances of the person with an intellectual disability and should always be considered.

The following approaches and treatments also include some of the more commonly used approaches with people who have an intellectual disability.[8]

Medical treatments include various types of prescribed medications and other treatment given by a doctor. Medication has a role to play in intervention for people with intellectual disabilities; however it should be used in conjunction with other interventions that provide the person with skills or life opportunities to manage their mental health problem. A GP should be consulted before taking any new medications or supplements. Medications should always be regularly reviewed by a doctor or psychiatrist.

Psychological treatments involve providing a supportive relationship and changing the way the person thinks or behaves. Usually it is talking face-to-face with a mental health professional, therapist or sometimes in a group to address issues and to promote personal growth and coping skills. Self-help books and computerised psychological treatments are also available.

Traditionally these types of therapy were thought to be inappropriate for people with an intellectual disability. Recent research, however, is showing that some of these can be appropriate and successful approaches. For example:

- *Cognitive Behaviour Therapy (CBT)* which uses a range of methods to change thoughts and behaviours that may be causing or maintaining inappropriate emotions.[26] Methods include relaxation training, problem solving, stress management and self-instructional training. The degree to which the type of CBT needs to be adapted and the benefits of it will depend on the person's level of intellectual disability, the problem it is being used to address and the therapist's understanding of intellectual disability.

- *Emotional awareness training* involves helping people to recognise emotions within themselves and others, as well as the links between their thoughts and emotions and behaviour.[26]

Positive Behaviour Support is a comprehensive approach encompasses learning principles and environmental interventions.
Interventions based on learning principles make the assumption that behaviour is learned, therefore it can be unlearned or re-learned.
Approaches may include specific skills training (e.g. relaxation, problem solving, anger management, and assertiveness), reinforcement/reward programs, systematic desensitisation and self-regulation/management approaches.
Lifestyle or environmental interventions focus on making adjustments to the person's lifestyle or environment. e.g. daily routines, increased or, decreased stimulation, exercise and diet.

Complementary treatment and lifestyle changes. Involve using natural or alternative therapies and changing the way one lives. Care should be taken to ensure that the self-help strategies employed are based on evidence or have been recommended by an appropriate professional.

Art therapies use art, music, dance or drama as a means for the expression of emotion and to teach solutions to emotional difficulties. They can help a person with ID to raise their self-esteem, acquire new skills and positive experiences, reduce anxiety and improve self-expression.[12]

Support groups bring people with common problems together who share experiences and help each other. Participation in mutual aid self-help groups can help reduce feelings of isolation, increase knowledge, enhance coping skills and bolster self-esteem. Family and friends can also be an important source of support for a person.

Rehabilitation programs help people regain skills and confidence to live and work in their community.

Family and friends are a very important source of support for a person with a mental illness. Family and friends can help by having an understanding of the illness and providing the same support as they would if the person has a physical illness. In looking to family and friend for support for the person with an intellectual disability it is important to keep in mind that they may be under stress or "burnt out" due to their burden of care.

Mental health first aid can continue to play an important role during this period when the person is receiving treatment if relapses or crises occur. At such times, people need to be supported by those around them, in particular when no expert help is immediately available.

Professionals who can help

A variety of health professionals can provide help to a person with a mental illness: Part of comprehensive management of the person's mental health problems may involve participation in a consultation with a specialist such as a disability service and/or the person's GP. These may often lead to referral for some form of treatment or therapy.

The health professional may require input and support from those caring for or supporting the person with an intellectual disability. They will not necessarily have an understanding of intellectual disability and the implications for the person's communication and ability to process information.
Ideally the following professionals would have an understanding of or experience in intellectual disability. This would help them to recognise the need to adapt their approach for the person perhaps incorporating the use of charts, pictures, photos, drawing, diaries and other concrete visual means.

General practitioners (GPs)

For many people developing a mental illness, their GP will be the professional they first turn to for help. A GP can recognise symptoms of a mental illness developing and provide the following types of help:

- Look for a possible physical cause
- Explain the illness and how the person can best be helped
- Prescribe medication if needed
- Refer the person to a psychologist or allied health professional who can help the person learn ways of coping and overcoming the illness
- Refer the person to a psychiatrist particularly if the symptoms are severe or long-lasting
- Link the person to community supports.

Psychologists

A psychologist is someone who has studied human behaviour at university and has had supervised professional experience in the area. Psychologists are registered with a national registration board. Some psychologists provide treatment to people with mental illnesses.

Psychologists do not have a medical degree, so do not prescribe medication. Some psychologists work for health services, while others are private practitioners.

A *clinical psychologist* is a psychologist who has undergone additional specialist training in how to treat people with mental health problems. They are particularly skilled at providing cognitive behaviour therapy and other psychological treatments. Many are members of the Australian Psychological Society's College of Clinical Psychologists.

As part of a Mental Health Care Plan, a GP can refer a patient to a psychologist. The cost of treatment is then fully or partly covered by Medicare. Psychologists vary in the amount they charge per session. Medicare will cover up to 12 individual sessions and 12 group sessions per calendar year. The following types of treatment are covered by Medicare:

- Psycho-education (providing information about a mental health problem and how to manage it)
- Cognitive behaviour therapy
- Relaxation strategies
- Skills training (including problem solving skills, anger management, social skills, communication training, stress management, and parent management training)
- Interpersonal therapy.

Psychiatrists

Psychiatrists are medical doctors who specialise in the treatment of mental illnesses. Psychiatrists mostly focus on treating people with severe and or long-lasting mental illnesses. They are experts in medication and can help people who are having side effects from their medication or interactions with other medications. It is possible to see a psychiatrist by getting a referral from a GP. A GP might refer a patient to a psychiatrist if they are very ill or are not getting better quickly. Most psychiatrists work in private practice, but some work in clinics or hospitals.

Occupational therapists and social workers

Most occupational therapists and social workers work in health or welfare services. However, a small number work as private practitioners in the mental health field and are registered by Medicare. They can provide similar treatments to psychologists. The cost is fully or partly covered by Medicare if there is a referral from a GP who has drawn up a Mental Health Care Plan.

Counsellors

Counsellors can provide psychological support. However, counsellors are not a profession registered by the government, so anyone can call themselves a counsellor without any qualifications. A well-qualified counsellor may also be a psychologist or other registered professional. Some counsellors may have specific training and skills in an area such as drug and alcohol counselling. Unless a counsellor is registered by Medicare, the client cannot claim a rebate and will have to pay the full fee.

Mental health nurses

Mental health nurses are registered nurses who are specialised in caring for people with mental illnesses. They generally care for people with more severe illnesses who are treated in hospitals or in the community. They can provide assistance with medication, practical support and counselling.

Case managers

Case managers work mainly with people with severe or complex mental illness and are often attached to mental health services. A case manager may be one of any number of mental health professionals, and have a variety of roles. Types of help that case managers can provide include monitoring the mental health of their clients, make suggestions about different sorts of ongoing therapy and recommending a medication review from time to time. A case manager will liaise with other members of the treatment team as described above. They may also liaise with social services and families.

Disability services

Thought should be given to whether it is best for the person with an intellectual disability to see a professional who has experience working with people who have intellectual disability. Psychologists with this kind of experience usually work in specialist services for people with a disability, both in the government and non-government sector. These can be located by contacting the government agency in your state that has responsibility for people with a disability, via the White Pages or via an internet search. (See helpful resources Section 1.2 *Mental Health First Aid and Intellectual Disability* for website details).

If the person is not already linked in with a disability service, a referral should be considered, taking note of the decision-making capacity and wishes of the person with an intellectual disability. If the person is being supported by a disability service, they may already have a GP, psychologist, counsellor or psychiatrist who they regularly see. If so, you may need to provide them with support to access this person.

Your state government disability service may be able to help locate a psychiatrist with experience treating people with intellectual disability.

It may also be useful to talk with the intake officer at the agency about their providing case management for the person you are concerned about, if this needed. You should seek consent for this from the person if they can give it, or from their legal guardian.

Recovery

Recovery refers to the lived or real life experiences of people as they accept and overcome the challenge of their illness. Recovery is much more than achieving the absence of symptoms, and means different things to different people. Recovery has been described as

> "a way of living a satisfying, hopeful and contributing life even with the limitation caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness".[27]

Some of the cornerstones of recovery are hope, willingness and responsible action by both the ill person and the helpers, education, self-advocacy and support.[28,29]

People recover from mental illness. Mental illness affects people differently and the recovery journey is different for each person. Recovery can progress slowly and it may also take time. Many different factors contribute to recovery. These may include having good support from family and friends, having a meaningful role in society through employment or education opportunities, getting professional help early, getting the best possible treatments and the person's willingness and ability to take up the opportunities available.

Mental health is everyone's business.[30] The attitudes and beliefs that society has about mental illness have a powerful impact on someone's illness and their recovery.

1.2 MENTAL HEALTH FIRST AID AND INTELLECTUAL DISABILITY

Where's Wally

1.2 Mental Health First Aid and Intellectual Disability

First Aid is the help given to an injured person before medical treatment can be obtained. The aims of any first aid course are to:

1. Preserve life
2. Prevent further harm
3. Promote recovery
4. Provide comfort to the person who is ill or injured.

Mental health first aid is the help provided to a person developing a mental health problem or experiencing a mental health crisis. The first aid is given until appropriate professional help is received or until the crisis resolves.

The aims of mental health first aid are to:

1. Preserve life where a person may be a danger to themselves.
2. Provide help to prevent the mental health problem from becoming more serious
3. Promote recovery of good mental health
4. Provide comfort to a person suffering with a mental health problem.

Mental health first aid will typically be offered by someone who is not a mental health professional but rather by someone in the person's social network (such as a family, friend or work colleague) or someone working in a human service occupation, e.g. teacher, police officer, employment agency worker, disability worker.

The Mental Health First Aid course teaches how to recognise the cluster of symptoms of different illnesses and mental health crises, how to offer and provide initial help and how to guide a person towards appropriate treatment and other supportive help. **The Mental Health First Aid course does not teach people to prove a diagnosis or therapy.**

Why Mental Health First Aid?

There are many reasons why people need training in mental health first aid:

- **Mental health problems are common,** especially depression, anxiety, and misuse of alcohol and other drugs.[3] In Australia, almost one in two adults have experienced a mental illness at some time and, during the past year, approximately one in five will have been affected.[6] Throughout the course of any person's life, it is highly likely that they will either develop a mental health problem themselves of have close contact with someone who does.

- **Many people are not well informed** about how to recognise mental health problems, how to respond to the person, and what effective treatments are available.[31] There are many myths and misunderstandings about mental health problems. Common myths include the idea that people with mental illnesses are dangerous, that it is better to avoid psychiatric treatment, that people can pull themselves out of mental health problems through will-power, and that only people who are weak get mental health problems. Lack of knowledge may result in people avoiding or not responding to someone with a mental health problem, or avoiding professional help for themselves. With greater community knowledge about mental health problems, people will be able to recognise problems in others and be better prepared to offer support.

- **Many people with mental health problems do not seek help or delay seeking help**. In Australia, only 35% of the people who had a mental illness in the past year received professional help for their problem.[6] Even when people seek treatment, many wait for years before doing so. The longer people delay getting help and support, the more difficult their recovery can be.[7] People with mental health problems are more likely to seek help if someone close to them suggests it.[24, 25]

- **There is a stigma associated with mental health problems.** Stigma involves negative attitudes (prejudice) and discrimination refers to negative behaviour. Stigma may have a number of negative effects. It may lead people to hide their problems from others. People are often ashamed to discuss mental health problems with family, friends, teachers and/or work colleagues. It may also hinder people from seeking help.[32] They may be reluctant to seek treatment and support for mental health problems because of their concerns about what others will think of them. Stigma can lead to the exclusion of people with mental health problems from employment, housing, social activities and having relationships. People with mental health problems can internalise the stigma so that begin to believe the negative things that others say about them. Better understanding of the experiences

of people with mental health problems can reduce prejudice and discrimination.

- **People with mental health problems may at times not have the insight** that they need help, or may be unaware that effective help is available for them. Some mental health problems can cloud a person's thinking and rational decision-making processes or the person can be in such a severe state of distress that they cannot take effective action to help themselves. In this situation, people close to them can facilitate appropriate help**.**

- **Professional help is not always available** when a mental health problem first arises. There are professional people and other support services that can help people with mental health problems. When these sources of help are not available, members of the public can offer immediate first aid and assist the person to get appropriate professional help and supports.

- **Mental health first aid has been found to be effective.** A number of research studies have shown that training in Mental Health First Aid results in better knowledge, attitudes and help-giving.[33-36]

General tips for working with people who have an intellectual disability and mental health problems

The following tips should be applied when attempting to implement any of the Mental Health First Aid Action Plans with a person who has an intellectual disability. [14,22,37,38]

- use **appropriate language**
  - speak clearly and slowly
  - speak in a calm, quiet voice
  - use simple, short statements or questions
  - avoid using abstract ideas and jargon
  - be specific
  - use a normal tone, don't shout or raise your voice
  - use non-threatening language (including body language)

- Ask **one question** or make **one request at a time.** Keep the conversation simple

- **Avoid using leading questions**. People with intellectual disability are often suggestible and will tell you what they think you want to hear or what they think is the 'right' answer

- **Use open questions** where possible, e.g. "how are you feeling?" or "tell me about……". Closed questions may be useful to clarify something, however be careful they are not leading questions

- Stop from time to time and **check the person's understanding**. If you are not sure that they have understood ask them to explain to you in their own words what you have just asked or told them

- **Don't assume** that the person's ability to express themselves is an indication of how much they understand or vice versa

- **Be patient,** give the person **time to respond**

- **Don't assume** the person with an intellectual disability will be able to **generalise skills** learnt in one context or situation automatically to another

- **Don't pretend to understand if you don't.** Use checking questions or paraphrasing to assist your understanding. Ask them to repeat what they have said in another way if they can

- Ask the person or their carer/support person if they have a preferred or **augmentative method of communicating.** Use **visual aids** when appropriate if possible. The use of drawings, pictures, etc can help you to give information in a way the person may be more likely to understand

- Be prepared to **repeat the information** more than once if necessary

- **Listen** to the person. **Don't be judgemental, critical or flippant** in your response

- Appear **calm, relaxed and confident**

- **Reassure** the person

- **Keep an upbeat attitude** and let them know you are available and supportive

- **do not make any promises that can't be kept**

- Ensure the **privacy, respect and dignity** of the person

- If the person is alone **ask whether they have family or a support worker that you can contact.** They may have contact details for these people in their wallet/purse.

Comprehensive management of mental health problems in people with intellectual disability

This manual is about providing First Aid to the person with an intellectual disability who is experiencing an emotional crisis due to a mental health problem. However it is also useful to understand the bigger picture in meeting their needs. Long term and lasting help can only be achieved when they receive comprehensive services by individuals and services supporting them. For this to occur:

- Management of mental health problems needs to be part of a broader service plan for the person. e.g. an Individual Plan (IP)

- A range of disciplines should contribute to the management of mental health problems. These might include psychiatrists, behaviour intervention clinicians, counsellors, GPs

- These professionals will require good information about the person with an intellectual disability. It is important that a support person knows the client well

- There should be a plan for managing the issues that arise out of the person's mental health problems. This should include procedures for handling difficult situations such as angry outbursts, withdrawal, threats of self harm, and for the use of emergency medication (PRN).

The Mental Health First Aid Action Plan

Before being able to give mental health first aid, first aiders need some basic knowledge about mental health problems so that they may be able to recognise that a disorder may be developing. It is important that the first aider does not ignore the symptoms they have noticed or assume that they will just go away. If a first aider believes the person they care about is experiencing symptoms of mental illness, they should approach the person and see if there is anything they can do to assist them.

Having an action plan can help to do this more effectively. In any first aid course, participants learn an action plan for the best way to help someone who is injured or ill. The most common mnemonic used to remember the procedure for this is DRABC(D), which stands for Danger, Response, Airway, Breathing, and Compressions (Defibrillation). The first aider will not always need to apply all actions as it will depend on the condition of the injured person. For example, one the first aider determines that the person is fully conscious, the subsequent actions of ABC(D) are not needed.

Similarly, the Mental Health First Aid Program provides an action plan on how to help a person in a mental health crisis or developing mental health problems. Its mnemonic is ALGEE (see box). Although the action of assisting with a crisis is the highest priority, the other actions in the Mental Health First Aid Action Plan may need to occur first. Therefore these actions are not necessarily steps to be followed in a fixed order. They are numbered purely to help remember them. The helping person has to use good judgment about the order and the relevance of these actions and needs to be flexible and responsive to the person they are helping. Listening non-judgmentally is an action that occurs throughout the giving of first aid.

MENTAL HEALTH FIRST AID

Mental Health First Aid Action Plan for People with an Intellectual Disability

1. **Approach the person , assess and assist with any crisis**
2. **Listen non-judgementally**
3. **Give support and information**
4. **Encourage and support the person to get appropriate professional help.**
   The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered
5. **Encourage other supports**.
   The person with an intellectual disability may need assistance to do this

When interacting with a person with an intellectual disability it is always important to;

- ***Speak in a calm quiet voice***
- ***Focus on one topic at a time. Because the person may be confused, keep your conversation simple.***
- ***Be patient and wait for responses.***
- ***Keep an upbeat attitude and let the person know that you are available and supportive.***

ACTION 1:
Approach the person, assess and assist with any crisis

The initial task is to approach the person, look out for any crises and assist the person to deal with them. In a situation involving a person with a mental health problem, the possible crises are that:

- the person may harm themselves (e.g. by attempting suicide, by using substances to become intoxicated, or by engaging in non-suicidal self-injury);
- the person experiences extreme distress(e.g. such as a panic attack, a traumatic event or a severe psychotic state);
- the person's behaviour is very disturbing to others (e.g. if they become aggressive, or lose touch with reality).

If the first aider has no concerns that the person is in crisis, they can ask the person about how they are feeling and how long they have been feeling that way and move onto ACTION 2.

When asking questions of a person with an intellectual disability it is important to:

- Communicate in a way that will assist them to understand e.g. by using visual aids,
- Check they have understood what you are asking by getting them to tell you in their own words, pictures, signs what they think you are asking them.
- Avoid asking leading questions.
- Be aware that people with an intellectual disability will often answer in the affirmative in order to please or appear capable, so check that what they say is what they really mean.

ACTION 2:
Listen non-judgementally

Listening to the person is a very important action. When listening, it is important to set aside any judgements made about the person or their situation, and avoid expressing those judgements. Most people who are experiencing distressing emotions and thoughts ant to be listened to empathetically before being offered options and resources that may help them. When listening non-judgementally, the first aider adopts certain attitudes and uses verbal and non-verbal listening skills that:

- Allow the listener to really hear and understand what is being said to them, and
- Make it easier for the other person to feel they can talk freely about their problems without being judged.

It is important to listen non-judgementally at all times when providing mental health first aid.

ACTION 3:
Give support and information

Once a person with a mental health problem has felt listened to, it can be easier for the first aider to offer support and information. The support to offer at the time includes emotional support, such as empathising with how they feel and giving them the hope of recovery, and practical help with tasks that may seem overwhelming at the moment. Also, the first aider can ask the person if they would like some information about mental health problems.

ACTION 4:
Encourage and support the person to get appropriate professional help

The first aider can also tell a person about any options available to them for help and support. A person with mental health problems will generally have a better recovery with appropriate professional help. However, they may not know about the various options that are available to them, such as medication, counselling, psychological therapy, disability services, support for family members, assistance with vocational and educational goals, and assistance with income and accommodation.

The person with an intellectual disability may need additional support to find this kind of help and to take advantage of what is available. These professionals will require good information about the person with an intellectual disability, so it is important to involve a support person who knows the person well.

You may need to stay with them longer or, if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access this professional. Pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.[21]

It is important to take with you to any professional's appointment any information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

ACTION 5:
Encourage other supports

Encourage and support the person to use self-help strategies and to seek the support of family, friends and others. In looking to of the person with an intellectual disability for support, it is important to keep in mind that they may be under stress or 'burnt out' due to their burden of care.

Other people who have experienced mental health problems can also provide valuable help in the person's recovery.

It is important to care for yourself

After providing mental health first aid to a person who is in distress, you may feel worn out, frustrated or even angry. You may also need to deal with the feelings and reactions you set aside during the encounter. It can be helpful to find someone to talk to about what has happened. If you do this, though, you need to remember to respect the person's right to privacy; if you talk to someone, don't share the name of the person you helped, or any personal details which might make them identifiable to the person you choose to share with.

When providing mental health first aid to a person not from you own cultural background, always be culturally competent and practice cultural safety.

Cultural competence

Being culturally competent when providing mental health first aid involves;

- Being aware that a person's culture will shape how they understand health and ill-health
- Learning about specific cultural beliefs that surround mental illness in the person's community
- Learning how mental illness is described in the person's community (knowing what words and ideas are used to talk about the symptoms or behaviours)
- Being aware of what concepts, behaviours of language are taboo (knowing what might cause shame).

Cultural safety

Practicing cultural safety means:

- Respecting the culture of the community by using the appropriate language and behaviour
- Never doing anything that cause the person to feel shame
- Supporting the person's right to make decisions about seeking culturally-based care.

Applying the MHFA Action Plan to developing mental health problems and crises

Section 2 of the manual explains how to apply the Mental Health First Aid Action Plan to a person with an intellectual disability who may be developing one or more of the following mental health problems:

- Depression
- Anxiety
- Psychosis
- Substance misuse

Section 3 of the manual describes the best ways to assess and assist a person with an intellectual disability who is experiencing a mental health crisis. The following are covered:

- Suicide thoughts and behaviours
- Non-suicidal self-injury
- Panic attacks
- Traumatic events
- Severe psychotic states
- Severe effects from alcohol misuse
- Severe effects from drug misuse
- Aggressive behaviours

HELPFUL RESOURCES

The following resources are particularly relevant for people with an intellectual disability who have a mental health problem or are suffering from a mental illness, their carers, support workers and families.

Websites

Government Disability Department Websites.
The following are the websites for government disability services in each state or territory.

NSW Department of Ageing Disability and Homecare
http://www.ADHC.nsw.gov.au

Disability South Australia
http://www.disability.sa.gov.au

Disability WA
http://www.disability.wa.gov.au

Tasmanian Dept of Health & Human Services
http://www.dhhs.tas.gov.au

Northern Territory Dept of Health & Families
http://www.health.nt.gov.au

Victorian Dept of Human Services
http://www.dhs.vic.gov.au

ACT Dept of Disability, Housing & Community Services
http://www.dhcs.act.gov.au

Disability Services QLD
http://www.disability.qld.gov.au

Queensland Centre for Intellectual and Developmental Disabilities.
http://www.som.uq.edu.au/research/qcidd/default.asp

QCIDD supports people with intellectual disability through research, teaching and clinical activities. Formerly known as DDU (Developmental Disability Unit), it is part of the School of Medicine at the University of Queensland. It is located at the Mater Misericordiae Public Hospitals in South Brisbane. Joint funding by the Department of Disability Services Queensland and Queensland Health makes QCIDD possible.

Centre for Developmental Disability Health
http://www.cddh.monash.org/

An academic unit established by the Victorian State Government to improve health outcomes for people with developmental disabilities through a range of educational, research and clinical activities. Provides some excellent information, resources and links regarding intellectual disability and health/mental health.

Australian Psychological Society
http://www.psychology.org.au/

A website which provides general information on many mental health areas as well as a find a psychologist tool by area and speciality.

The National Association for the Dually Diagnosed (NADD)
http://www.thenadd.org

NADD is the leading North American expert in providing professionals, educators, policy makers, and families with education, training, and information on mental health issues relating to persons with intellectual or developmental disabilities. The mission of NADD is to advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care.

Commonwealth Carelink Centres
http://www9.health.gov.au/ccsd/

In some states services have been set up to provide respite specifically for families or carers involved with a person who has intellectual disability and mental health problems. The Commonwealth Government website provides access to contacts for local respite services, some of which may offer such a service.

Mental Health Net Directory
www.mentalhelp.net

An American based website with general information on vast array of mental health issues, with links to many countries.

Foundation for People with Learning Disabilities.
http://www.learningdisabilities.org.uk/

A British organisation that is part of the Mental Health Foundation, a national charity. The Foundation for People with Learning Disabilities produces a range of publications, including reports, briefings and information booklets. Most of these can be downloaded free of charge from this site.

British Institute of Learning Disabilities. (BILD)
http://www.bild.org.uk/index.html

This organisation is involved in policy development and research and provides learning services and publications (books, journals, training materials).

University of Birmingham LD Medication Guideline
http://www.ld-medication.bham.ac.uk/medical.shtml

This website had both easy read leaflets and audio recordings that may help a person with an intellectual disability to understand their medication.

Understanding Intellectual Disability and Health
http://www.intellectualdisability.info/mental-health

This is part of University of London website that aims to provide an understanding of the nature of intellectual disability is essential for health care professionals, who are required to support equal access to their services for all disabled people.

Pavilion Publishing
http://www.pavpub.com/pavpub/home/

This publishing company publishes a number of manuals, training resources and books on Intellectual Disability and Mental Health.

Training

Remind Mental Health Training and Education
remind@sfnsw.org.au

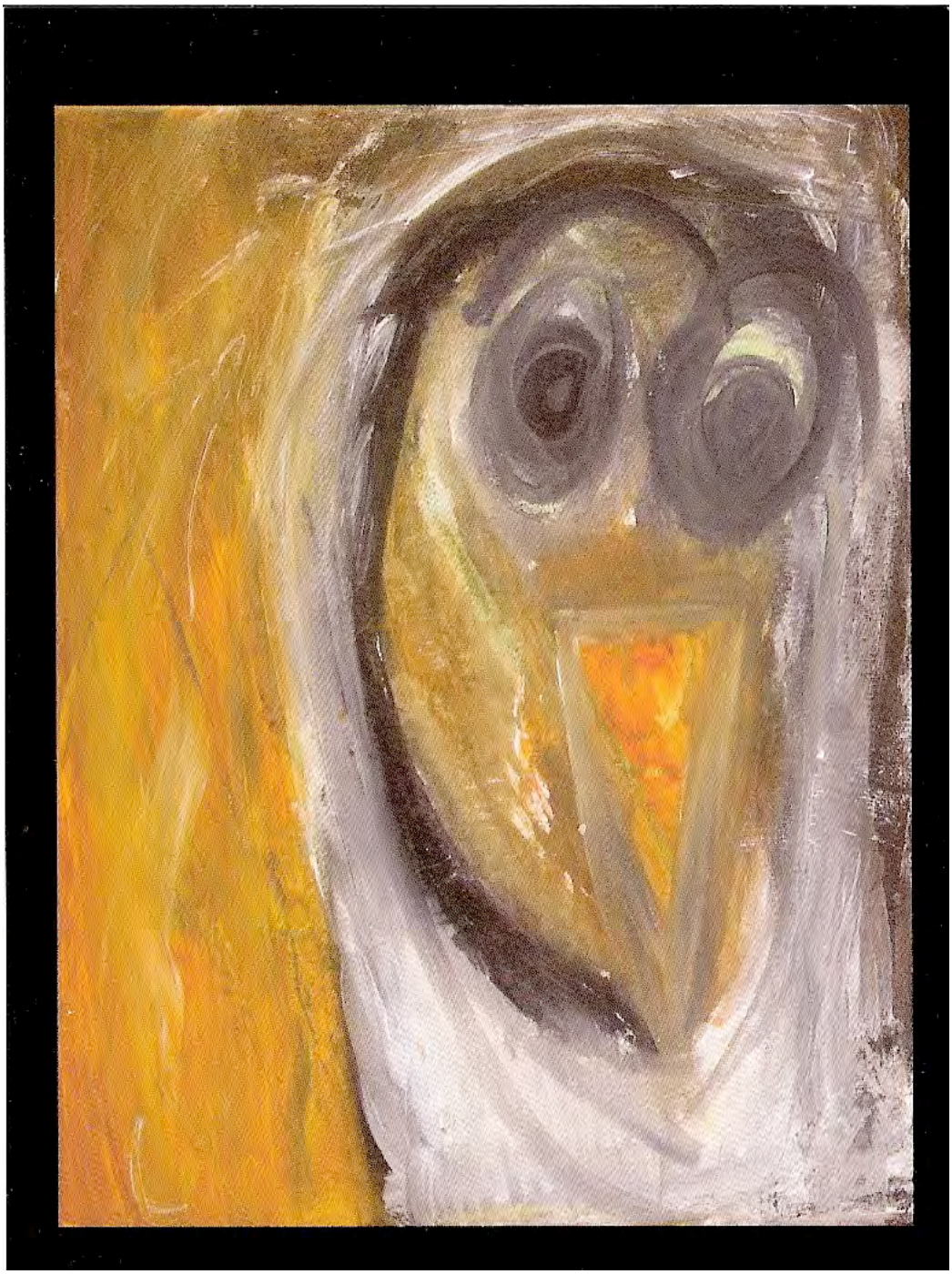
Remind provide a 2 day specialist workshop for workers providing services to clients with a dual diagnosis (mental illness & intellectual disability). They present from a family/carer perspective. Workshops are conducted across NSW.

SECTION 2

First Aid for Developing Mental Health Problems and Intellectual Disability

Bright and Beautiful

2.1 DEPRESSION



Owl

2.1 Depression

What is depression?

The word "depression is used in many different ways. People feel sad or blue when bad things happen. However, everyday 'blues' or sadness is not a depressive disorder. People with the 'blues' may have a short-term depressed mood, but they can manage to cope and soon recover without treatment. The depression we are talking about in this chapter is major depressive disorder, a type of mood disorder. Major depressive disorder lasts for at least two weeks and affects a person's ability to carry out their work and usual daily activities and to have satisfying personal relationships.

Mood disorders affect 6.2% of Australians aged 16-85 years in a given year.[3] The most common mood disorder is major depressive disorder which affects 4.1% in any one year; 5.1% of females and 3.1% of males. The median age of onset is 25 years[15] which means that half the people who will ever have an episode of mood disorder will have had their first episode by this age. Depression often occurs with anxiety disorders and substance use disorders.[39]

Depression is the most common mental disorder experienced by people with intellectual disability. Prevalence rates between 1.3 and 3.7% have been reported.[14] It has been argued that these rates are underestimates because of the problems involved in diagnosing depression in a population who commonly have communication deficits. Rates are likely to be much higher than in the general population. Some suggest it is as high as 40-50% of people with an intellectual disability. There is a higher prevalence of depression in those with Down Syndrome.[40]

Depression is more common in females than males. It is often recurrent (that is, people recover but develop another episode later on). Once a person has had an episode of depression, they become more prone to subsequent episodes during their life.[41]

The box below lists the signs and symptoms of depression.[2] Not every person who is depressed has all these symptoms. People differ in the number of symptoms they have and also how severe the symptoms are. Even if a person does not have enough symptoms to be diagnosed with a depressive disorder, the impact on their life can still be significant.

Signs and symptoms of major depressive disorder

If a person is clinically depressed they would have at least five or more of these symptoms (including at least one of the first two) nearly every day for at least two weeks.

- an unusually sad mood
- loss of enjoyment and interest in activities that used to be enjoyable
- lack of energy and tiredness.
- feeling worthless or feeling guilty when they are not really at fault
- thinking about death a lot or wishing to be dead
- difficulty concentrating or making decisions
- moving more slowly or sometimes becoming agitated and unstable to settle
- having sleeping difficulties or sometimes sleeping too much
- loss of interest in food or sometimes, eating too much. Changes in eating habits may lead to either loss of weight or putting on weight.

The following are indicative of more severe signs and symptoms in those with an intellectual disability.[37,42] The more severe the level of disability the more likely the first four are to be expressed due to a decreased ability to verbally communicate thoughts and feelings.

- increase in tearfulness
- deterioration in social and self-help skills.
- irritability instead of sadness
- aggression and self injurious behaviour
- property damage
- decreased appetite
- severe sleep disturbance
- weight loss
- total social withdrawal
- unwillingness to use speech
- slowness in thought and movement

Some of the symptoms of depression experienced by the general population may actually be a part of the 'usual' presentation of a person with an intellectual disability. This doesn't mean, however, that they aren't symptomatic of depression. The person may have been depressed for quite some time, but it may have been undetected. It is important therefore not to make assumptions, for example, "oh that's just him", "she always looks like that". There may be gradual or sudden changes in behaviour patterns and or presentation.

It can also be helpful to try and identify whether the person has undergone any negative life experiences in recent times. People who have depression and intellectual disability have often experienced one or more significant negative life events, e.g. loss of significant people, abuse, medical illness, being moved.[37] It is important to understand how significant seemingly minor changes can be for a person with an intellectual disability.

It is also helpful to consider the possible side effects of any medication.

People with ID may not be able to easily communicate their feelings in words. Some may not realise they are depressed, especially if they have been feeling that way for a long time.[22] In those with a moderate or mild intellectual disability, the person may be able to describe the symptoms. However in those with more severe disability observation of behavioural changes and third party reports from family and direct care providers may need to be more heavily relied on.

The following table outlines the signs and symptoms for a major depressive episode used for the general population and the equivalent for people with an intellectual disability.[12,37,42] Mental health problems may be suspected when the features below represent a change from the person's usual presentation.

Signs and Symptoms in the General Population	Intellectual Disability Equivalents
1. Depressed or irritable mood	Apathetic, sad or angry facial expression; lack of emotional reactivity; upset; crying; tantrums; verbal and physical aggression that don't match the situation
2. Markedly diminished interest or pleasure in most activities	Withdrawal; loss of interest in usual reinforcers (rewarding activities); refusal to participate in favoured leisure activities or work; change in ability to watch TV or listen to music, unable to be cheered up
3. Significant weight loss; decrease or increase in appetite	Tantrums at meals; refusal to eat or lack of interest in food, stealing food; refusing activities; hoarding food in room
4. Difficulty sleeping or sleeping too much	May or may not be able to self-report sleep problems; if living with others or in a staffed situation, others/staff may report going to bed quite late; any change in sleeping habits; difficulty going to sleep; being up during the night; difficulty waking or waking very early; frequent day time napping; tantrums or activity during sleeping hours; noted sleeping or napping during the day
5. Rapid or slowed thought and movement	Pacing, hyperactivity, restlessness or being fidgety, decreased energy, passivity; development of obsessional slowness in activities of daily living; increase or decrease in vocalizations or speech, muteness; whispering; monosyllables; increase in self-injurious behaviour or aggression that don't match the situation.
6. Fatigue or loss of energy	Appears tired, tiring quickly; refuses leisure activities or work, withdraws to room; loss of daily living skills; refusal to perform personal care tasks; incontinence due to lack of energy/motivation to go to the bathroom; work production decrease; lack of interest in joining activities; just watches TV; sitting for long periods of time.

Clinical Criteria	Intellectual Disability Equivalents
7. Feelings of worthlessness	Statements such as "I'm stupid", "I'm bad", "I'm not normal", "nobody likes me", seeming to seek punishment blaming themselves. If someone is nonverbal or has difficulty communicating verbally to express their displeasure frustration or depression they are left with little else but to express this through often aggressive or self harm behaviours.[37]
8. Diminished ability to think or concentrate	Poor performance at work; change in leisure habits and hobbies; appearing distracted, decrease in completion of tasks; needing more instruction or support to complete tasks; loss of previously mastered skills; decrease in IQ upon testing.
9. Recurrent thoughts of death; suicidal behaviour or statements	Preoccupation with the deaths of family members and friends; preoccupation with funerals; fascination with violent TV shows/movies; spontaneous comments about death; talking about committing suicide;
	Other symptoms may include excessive need for reassurance, unresponsiveness to preferred staff, complaints of unspecific aches and pains.

How a depressed person may appear

A person who is depressed may be slow in moving and thinking, although agitation can occur. Even speech can be slow and monotonous. There can be a lack of interest and attention to personal hygiene and grooming. The person usually looks sad and depressed, and is often anxious, irritable and easily moved to tears. However, in mild depression the person may be able to hide their depression from others, while with severe depression the person may be emotionally unresponsive and describe themselves as "beyond tears". Their thinking often has themes of hopelessness and helplessness, with a negative view of self ("I'm a failure", "It's all my fault", "Nothing good ever happens to me", "I'm worthless", "No-one loves me"), the world ("Life is not worth living", "There is nothing good out there") and the future ("things will always be bad").

The difference between depression and grief

It is important not to confuse grief with depression. Grief is a normal response to loss. The length of time someone grieves and the way in which they do so is very individual. Unresolved grief and multiples losses over time may increase the risk of someone becoming depressed.

People with an intellectual disability do experience grief and loss, even though they may not understand the concept of death. It is important to remember that due to their cognitive and communicative deficits:

- they may express grief differently to those without a disability and
- the mourning process may take longer.

This may lead to the behavioural expression of grief being misdiagnosed as challenging behaviour or depression.

Other mood disorders

Bipolar disorder

People with bipolar disorder (previously called *manic depressive disorder)* have extreme mood swings. They can experience periods of depression, periods of mania and long periods of normal mood in between. The time between these different episodes can vary greatly from person to person.

The *depression* experienced by a person with bipolar disorder includes some or all of the symptoms of depression listed previously. *Mania* appears to be the opposite of depression. A person experiencing mania will have an elevated mood, be over-confident and full of energy. The person might be very talkative, full of ideas, have less need for sleep, and take risks they normally would not. Although some of these symptoms may sound beneficial, e.g. increased energy and full of ideas, it often gets people into difficult situations, e.g. they could spend too much money and get into debt, they can become angry and aggressive, get into legal trouble or be sexually promiscuous. These consequences may play havoc with work, study and personal relationships. The person can have grandiose ideas and may lose touch with reality (that is, become psychotic).

In fact, it is not unusual for people with this disorder to become psychotic during depressive or manic episodes.[43, 44]

A person cannot be diagnosed with bipolar disorder until they have experienced both an episode of mania and an episode of depression. It may, therefore, take many years before they are diagnosed correctly and get the most appropriate treatment.

Approximately 1.8% of Australians aged 16-85 years experience bipolar disorder.[45] The median age of onset is 18 years, which means that half the people with bipolar disorder will have had their first episode at this age.[15] Bipolar disorder affects equal numbers of men and women.[6]

Additional information on bipolar disorder is discussed in Section 2.3 *Psychosis*

Seasonal affective disorder

Seasonal affective disorder is characterised by a depressive illness during the autumn and winter months, when there is less natural sunlight. Prevalence increases the further away from the equator. The depression generally lifts during spring and summer. People with seasonal affective disorder are more likely to experience the following symptoms of depression: lack of energy, sleeping too much, overeating, weight gain and a craving for carbohydrates.[2]

Risk factors for depressive disorders.

Depression has no single cause and often involves the interaction of many diverse biological, psychological and social factors.[45, 46]

People with an intellectual disability have little control over their lives and often don't have a choice about where they live, the people they live with, activities they participate in, who provides them with care, what they eat, what they wear etc, which can lead to depression.

The risks of developing depression and mood disorders are likely to be higher for people with an intellectual disability due to additional difficulties such as brain damage, higher rates of physical illness, communication impairment, poor social and coping skills and less social support.[14]

The following factors increase a person's risk of developing depression

- a history of depression in close family members
- a break-up or loss of a relationship. For people with an intellectual disability relationships could also include those at day/work placements, with support workers, carers, therapists, pets.
- living in conflict. Many people with an intellectual disability live in group care. They often have little choice about their placement and as a result the potential for living in conflict is much higher.
- placement changes.(e.g, accommodation, day options, vocational)
- being a more sensitive, emotional and anxious person
- adverse experiences in childhood, such as lack of car or abuse
- poverty, poor education and social disadvantage
- adverse events in the person's life recently, such as being a victim of crime, death or serious illness in the family, having an accident, bullying or victimisation, job loss
- long-term or serious physical illness
- having another mental illness, such as anxiety disorder, psychotic disorder or substance use disorder
- low self esteem and a lack of social skills necessary to obtain positive reinforcement[37]
- having a baby (10—15% of women suffer depression shortly after childbirth)
- pre-menstrual changes in hormone levels
- caring full-time for a person with a long-term disability.[47]
- an intellectual disability.

Depression can also result from:

- the direct effects of medical conditions, e.g. Parkinson's disease, Huntington's disease, stroke, Vitamin B12 deficiency, hypothyroidism, systemic lupus erythematosus, hepatitis, glandular fever, HIV, some cancers.[2]
- some syndromes associated with intellectual disability, such as Prader-Willi syndrome.
- the side effects of certain medications or drugs. People with intellectual disability are often on medication.

- lack of exposure to bright light in the winter months.

- intoxication or withdrawal from alcohol or other drugs.

Perinatal depression

Perinatal depression refers to depression that occurs in a woman at a time around childbirth. The depression can either occur before birth *(antenatal depression)* or after birth *(postnatal or postpartum depression)*. Feeling sad or having the "baby blues" after giving birth is common, but when these feelings last for more than two weeks, this may be a sign of a depressive disorder.

The symptoms do not differ from depression at other times, However, depression at this time has an impact not only on the mother, but also on the mother-infant relationship and on the child's cognitive and emotional development. For this reason, it is particularly important to get good treatment for post-partum depression. Treatment not only helps the mother's depressive symptoms, but can also improve the mother-child relationship and the child's cognitive development.[48]

A national survey of Australian woman 6-8 weeks after childbirth found that 7.5% of them had a major depressive disorder.[49] Factors that may contribute to this are hormonal and physical changes and the responsibilities of caring for a baby. Having had a previous episode of depression increases risk for postpartum depression and symptoms are often already present during pregnancy.

The symptoms of depression are thought to be due to changes in natural brain chemicals called neurotransmitters. These chemicals send messages from one nerve cell to another in the brain. When a person becomes depressed, the brain can have less of certain of these chemical messengers. One of these is serotonin, a mood regulating brain chemical. Many antidepressant medications work by changing the activity of serotonin in the brain.

Interventions for depressive disorders

Professionals who can help

A variety of health professionals can provide help to the person with depression. They are:

- GPs
- Psychologists
- Counsellors
- Psychiatrists
- Allied health professionals such as occupational therapists, social workers and mental health nurses.

More information about these professionals can be found in Section 1.1 *Mental Health Problems and Intellectual Disability in Australia*

Only in the most severe cases of depression, or where there is a danger a person might harm themselves, is a depressed person admitted to a hospital. Most people with depression can be effectively treated in the community.

As mentioned in the Section 1.2 *Mental Health First Aid and Intellectual Disability*, in addition to receiving first aid the person with an intellectual disability should also have a comprehensive management plan developed to address their mental health problem.

Treatments available for depressive disorders

Most people recover from depression and lead satisfying and productive lives. Below are a range of treatments available for depression.[50] Most of these have been used in some form with people with an intellectual disability and depression. However, apart from CBT and the more common medications, there is little research support for their effectiveness in people with an intellectual disability. Treatments for bipolar are described in Section 2.3 *Psychosis.*

Psychological therapies

There is good evidence for the following psychological therapies in the treatment of depression.

- ***Cognitive behaviour therapy (CBT)*** is based on the idea that how we think affects the way we feel. When people get depressed they think negatively about most things. There may be thoughts about how hopeless the person's situation is and how helpless the person feels, with a negative view of themselves, the world and the future. Cognitive behaviour therapy helps the person recognise such unhelpful thoughts and change them to more realistic ones. It also helps people to change depressive behaviours by scheduling regular activities and engaging in pleasurable activities. It can include components such as stress management, relaxation techniques and sleep management. The degree to which the type of CBT needs to be adapted and the benefits of it will depend on the person's level of disability, the problem it is being used to address and the therapist's understanding of intellectual disability.

- ***Interpersonal psychotherapy*** helps people to resolve conflict with other people, deal with grief or changes in their relationships, and develop better relationships.

- ***Marital therapy*** can help where there are relationship problems along with depression. It focuses on helping a person who is depressed by improving their relationship with their partner.

- ***Problem solving therapy*** involves meeting with a therapist to clearly identify problems, think of different solutions for each problem, choose the best solution, develop and carry out a plan, and then see if this solves the problem. In a broader sense and often not related to a mental health issue, some people with an intellectual disability have deficits in this area so the teaching and practice of these skills occurs as part of everyday life.

Research shows that there is an even better outcome when psychological therapy is given in combination with antidepressant medication

Medical Treatment

The following medical treatments are known to be effective.

- ***Antidepressant medications*** have been found to be effective with adults who have moderate to sever depression.

- ***Electroconvulsive therapy*** can be effective for people with severe depression that has not responded to other treatment. However, it has also been known to cause some negative side effects, such as memory loss. There are strict regulations guiding it's use. For example in NSW if the person is unable to provide consent the matter must be referred to the Mental Health Review Tribunal.

- ***Antipsychotic medications*** are used to treat people with bipolar disorder. They are also sometimes used to treat people with major depression, in combination with antidepressants, where other treatments have not worked.

Medications should be used, where possible in combination with other interventions that provide the person with skills to manage their mental illness. Medications should be frequently reviewed by a GP or psychiatrist.

Lifestyle and complementary therapies.

The following have some scientific evidence for effectiveness in helping with depression.

- ***Exercise*** including both aerobic (e.g. jogging, brisk walking) and anaerobic (e.g. weight training). Even incidental exercise is important. Exercise doesn't necessarily require a special program.

- ***SAMe*** (S- Adenosylmethionine) which is a compound made in the body and available as a supplement in health food stores.

- ***Self-help books*** which are based on cognitive behaviour therapy (see resources at end of this chapter). There are some that have been written especially for people with an intellectual disability. These are most useful under the guidance of a health professional.

- ***Computerised therapy*** which is self-help treatment delivered over the internet or on a computer. Some are available for free (see resources at the end of this chapter). These are most useful when used under the guidance of a health professional.

In relation to self-help books and computerised therapy, people with an intellectual disability would need some level of literacy to access these as well as perhaps additional assistance from family, a case worker or disability worker.

- ***Light therapy*** which involves bright light exposure to the eyes, often in the morning. This is most useful for seasonal affective disorder, when used under the guidance of a health professional. One study reports on an "adequate clinical response" when this treatment was used with two people with intellectual disability.[51]

- ***Increasing pleasant activities*** because depressed people engage in pleasant activities less often than other people and find fewer activities pleasant. Encourage and support the person to plan pleasant activities in advance. This will give them something to look forward to, as well as a sense of structure and control. Depressed people can increase the frequency of pleasant activities as a form of self-help, but is most useful when done under the guidance of a health professional.

There are a number of other complementary therapies which have weaker evidence as effective for depression. For further information see *A Guide to What Works for Depression* in the resources section of this chapter.

As well as looking at scientific evidence of what treatments and supports work for depression, it is also important to look at what people who have experienced depression find to be helpful. A large internet survey of people who have received treatment for a depressive disorder asked them to rate the effectiveness of any treatment they had had.[52] The treatments they rated as most effective were: some antidepressant medications, cognitive

behaviour therapy, interpersonal psychotherapy, other types of psychotherapy and exercise.

The following interventions have been found to be effective when working with a person with an intellectual disability and depression.

- ***Maintaining a normal routine***. Consistency will give the person a sense of normalcy, safety and of being supported. You need to be careful not to push or force the person into complying. This could result in the person becoming increasingly irritable. Over time this may lead to anger and challenging behaviour.

- ***Reducing irritations and demands*** on the person when loss of motivation is present.

- ***Educating the person and support staff about depression.***

Importance of early intervention for depression.

Early intervention is very important. People who wait a long time before getting treatment for depression tend to have a worse outcome.[53] Once a person has had an episode of depression they become more prone to subsequent episodes. They fall into depression more easily with each subsequent episode.[41] For this reason, some people go on to have repeated episodes throughout their life. To prevent his pattern occurring, it is important to intervene early with a first episode of depression to make sure it is treated quickly and effectively.

Crises associated with depression

Two main crises that may be associated with depression are:

- The person has **suicidal thoughts and behaviours**

- The person is engaging in **non-suicidal self-injury**

Suicidal thoughts and behaviours

Suicide is a significant risk for people with depression. Of Australians aged 16-85 who have had a depressive disorder in the past 12 months, approximately 4% attempt suicide.[54] A person may feel so overwhelmed and helpless that the future appears hopeless. The person may think suicide is the only way out. Sometimes a person becomes suicidal very quickly, perhaps in response to a trigger (such as a relationship break up or arrest), and act on their thoughts quickly and impulsively. The risk is increased if they have also been using alcohol or other drugs. However, not every person who is depressed is at risk for suicide and nor is everyone who is at risk of suicide necessarily depressed.

Suicidal thinking and high risk-taking behaviour in those with an intellectual disability should always be investigated. The method chosen by a person with an intellectual disability may not have any lethal potential but may have been chosen because the person believed it would be fatal, so the intent is still there.[12]

Non-suicidal self injury[55]

Non-suicidal self injury is also a significant risk for people with depression. People who engage in self-injury report more intense experience of emotional distress. They may also struggle to express these emotions. For these people, self-injury may alleviate their distress temporarily. Adults who engage in self-injury typically started doing so during adolescence, and it may have become a very difficult habit to break.

People with an intellectual disability, especially those with more significant levels, often engage in self injurious behaviour (SIB) for reasons that are unrelated to depression or a mental illness. SIB can be the result of the person's inability to communicate things like; boredom, loneliness, physical pain and a range of both positive and negative emotions to others. SIB may also be a related to a particular syndrome from which the person suffers (e.g. Smith Magenis Syndrome), or deficits relating to impulsivity and sensory sensitivities in a person with an intellectual disability.

Mental Health First Aid Action Plan for People with an Intellectual Disability and Depression[56,57]

1. **Approach the person , assess and assist with any crisis**
2. **Listen non-judgementally**
3. **Give support and information**
4. **Encourage and support the person to get appropriate professional help.**
   The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered
5. **Encourage other supports.**
   The person with an intellectual disability may need assistance to do this

ACTION 1:
Approach the person, assess and assist with any crisis

How to approach

If you think that someone you may know may be depressed and in need of help, approach the person about your concerns. It is important to choose a suitable time when both you and the person are available to talk, as well as a space where you both feel comfortable. Let the person know that you are available to talk when they are ready; do not put pressure on the person to talk right away. It can be helpful to let the person choose the moment to open up. However, if the person does not initiate a conversation with you about how they are feeling, you should say something to them. You should respect the person's privacy and confidentiality unless you are concerned that the person is at risk of harming themselves or others.
As you talk with the person, be on the lookout for any indications that the person may be in crisis.

When asking questions of a person with an intellectual disability it is important to:

- Communicate in a way that will assist them to understand e.g. by using visual aids,
- Check they have understood what you are asking by getting them to tell you in their own words, pictures, signs what they think you are asking them.
- Avoid asking leading questions.
- Be aware that people with an intellectual disability will often answer in the affirmative in order to please or appear capable so check that what they say is what they really mean.

*If you have concerns that the person may be having **suicidal thoughts**, find out how to **assess** and **assist** this person in section 3.1 First Aid for Suicidal Thoughts and Behaviours.*

*If you have concerns that the person may be engaging in **non-suicidal self-injury**, find out how to **assess** and **assist** this person in Section 3.2 First Aid for Non-Suicidal Self-injury.*

If you have no concerns that the person is in crisis, you can ask them about how they are feeling and how long they have been feeling that way and move on to ACTION 2

ACTION 2:
Listen non-judgementally

If you believe that the person is not in a crisis that needs immediate attention, you can engage the person in conversation, such as asking the person about how they are feeling and how long they have been feeling this way.
People with an intellectual disability often have trouble recognising their emotions and expressing them verbally. You may need to give them additional time to think and respond, as well as offer alternative means for them to tell you how or what they are feeling (e.g., pictorially, role play).
Listening non-judgementally is important at this stage as it can help the person to feel heard and understood, while not being judged in any way. This can make it easy for the person to feel

comfortable to talk freely about their problems and to ask for help.

Tips for non-judgemental listening

It is very difficult to be entirely non-judgemental all of the time. We automatically make judgements about people from the minute we first see or meet them, based on their appearance, behaviour, and what they say. **There is more to non-judgemental listening than simply trying not to make those judgements – it is about ensuring that you do not express your negative judgements, as this can get in the way of helping.** If you have decided to approach someone with your concerns about them it is a good idea to spend some time reflecting on your own state of mind first and ensure you are in the right frame of mind to express your concerns without being judgemental.

Although the focus of your conversation with the person you are helping is on their feelings, thoughts and experiences, you need to be aware of your own as well. Helping someone who is in distress may evoke an unexpected emotional response in you; you may find yourself feeling fearful, overwhelmed, sad or even irritated or frustrated. Privately acknowledge and work through these feelings.

In spite of any emotional response you have, you need to continue listening respectfully and avoid expressing a negative reaction to what the person says. This is sometimes difficult, and may be made more complex by your relationship with the person, your personal beliefs about their situation or the communication difficulties a person with an intellectual disability may have. **You need to set aside these beliefs and reactions in order to focus on the needs of the person you are helping; their need to be heard, understood, and helped.** Remember that you are providing the person with a safe space to express themselves, and a negative reaction from you can prevent them from feeling that sense of safety.

Effective communication skills for non-judgemental listening[58]

You can be an effective non-judgemental listener by paying special attention to two main areas.

- Your **attitudes**, and how they are conveyed
- Effective **communication skills** – both verbal and non-verbal

Attitudes

They key attitudes involved in non-judgemental listening are acceptance, genuineness and empathy.

Adopting an attitude of **acceptance** means respecting the person's feelings, personal values and experiences as valid, even if they are different from your own, or you disagree with them. You should not judge, criticise or trivialise what the person says because of your own beliefs or attitudes. Sometimes, this may mean withholding any and all judgements you have made about the person and their circumstances, e.g. listen to the person without judging them as weak – these problems are not due to weakness or laziness – the person is trying to cope.

Genuineness means that what you say and do shows the person that they are accepted. This means not holding one set of attitudes while expressing another. Your body language and verbal cues should reinforce your acceptance of the person. For example, if you tell the person you accept and respect their feeling, but maintain a defensive posture or avoid eye contact, the person will know you are not being genuine.

Empathy means being able to imagine yourself in the other person's place, showing them that they are truly heard and understood by you. This doesn't mean saying something glib such as "I understand exactly how you are feeling" – it is more appropriate to say that you can appreciate the difficulty that they may be going through. Remember that empathy is different from sympathy, which means feeling sorry for or pitying the person.

Verbal skills

Using the following simple verbal skills will show that you are listening:

- Ask questions which show that you genuinely care and want clarification about what they are saying.
- Check your understanding by re-stating what they have said and summarising fact and feelings.
- When listening to a person with an intellectual disability you may need to use more checking questions and paraphrasing to ensure that you have understood correctly. It is far better to ask the person to repeat what they said, or to say it in a different way than to pretend that you have understood them or to assume that they have understood you.
- Listen not only to what the person says, but how they say it; their tone of voice and non-verbal cues will give extra clues about how they are feeling. Observation of body language is important, especially so if the person has communication difficulties.

- Use minimal prompts, such as “I see” and “ah” when necessary to keep the conversation going.

- Be patient, even when the person may not be communicating well, may be repetitive or may be speaking slower and less clearly than usual.

- Do not be critical or express you frustration at the person for having such symptoms.

- Avoid giving unhelpful advice such as “pull yourself together” or “cheer up”. If this was possible the person would do it.

- Do not interrupt the person when they are speaking or expressing themselves, especially to share your opinions or experiences. People with an intellectual disability are often eager to ‘do the right thing’ or please others and may cease telling you about how they feel and start listening to you instead.

- Avoid confrontation unless necessary to prevent harmful or dangerous acts.

Remember that pauses and silences are okay. Silence can be uncomfortable for many people, but the person may need time to think about what has been said, or may be struggling to find the words they need. If the person has an intellectual disability they may need more time to use what ever means they are using to express themselves clearly. Interrupting the silence may make it difficult for them to get back on track, and may damage the rapport you have been building. Consider whether the silence is awkward, or just awkward for you.

Non-verbal skills

Non-verbal communications and body language express a great deal. Good non-verbal skills show that you are listening, while poor non-verbal skills can damage the rapport between you and the person you are assisting and negate what you say.

Keep the following non-verbal cues in mind to reinforce you non-judgemental listening:

- Pay close attention to what the person says.

- Maintain comfortable eye contact. Don’t avoid eye contact, but do avoid staring; you can do this by maintaining the level of eye contact that the person seems most comfortable with. Remember that some people (e.g. those with autism) may be uncomfortable with direct eye contact.

- Maintain an open body position. Don’t cross your arms over your body, as this may appear defensive.

- If it is safe, sit down, even if the person is standing. This may seem less threatening.

- It is best to sit alongside the person angled towards them, rather than directly opposite them.

- Don’t fidget.

Cultural considerations for non-judgemental listening

If you are assisting someone from a cultural background which is different from your own, you may need to adjust some of your verbal and non-verbal behaviours. For example, the person may be comfortable with a level of eye contact different from what you are used to, or may be used to more personal space.

If these differences are interfering with your ability to be an effective helper, it may be helpful to explore and try to understand the person’s experiences, values or belief systems. Be prepared to discuss what is culturally appropriate and realistic for the person, or seek advice from someone from their cultural background before speaking to them.

ACTION 3:
Give support and information

Treat the person with respect and dignity

Each person’s situation and needs are unique. It is important to respect the person’s autonomy while considering the extent to which they are able to make decisions for themselves. Equally, you should respect the person’s privacy and confidentiality unless you are concerned that the person is at risk of harming themselves or others.

Do not blame the person for their illness

Depression is a real health problem and the person cannot help being affected by depression. It is important to remind the person that they have a health problem and that they are not to blame for feeling “down”.

Have realistic expectations for the person

You should accept the person as they are and have realistic expectations for them. Everyday activities like cleaning the house, personal care, paying bills, feeding the dog, may seem overwhelming. You should let them know that they are not weak or a failure because they have depression, and that you don’t think less of them as a person. You should acknowledge that the person is not “faking’, “lazy”, “weak” or “selfish”.

Offer consistent emotional support and understanding

It is more important for you to be genuinely caring than for you to say all the "right things". The person genuinely needs additional care and understanding to help them through their illness so you should be empathic, compassionate and patient. People with depression are often overwhelmed by irrational fears; you need to be gently understanding of someone in this state. It is important to be patient, persistent and encouraging when supporting someone with depression. You should also offer the person kindness and attention, even if it is not reciprocated. Let the person know that they will not be abandoned. You should be confident, consistent and predictable in you interactions with the person.

Give the person hope for recovery

You need to encourage the person to maintain hope by communicating that, with time and treatment, they will feel better. Offer emotional support and hope of a more positive future in whatever form the person will accept.

Provide practical help

Ask the person if they would like any practical assistance with tasks, but be careful not to take over or encourage dependency. People with an intellectual disability are already vulnerable to over-dependency.

Offer information

Ask the person if they would like some information about depression. If they do want some information, it is important that you give them resources and information that are accurate and appropriate to their situation. Don't assume that the person knows nothing about depression as they, or someone else close to them, may have experienced depression before.

For people with an intellectual disability, information and reassurance needs to be given in a way that will promote understanding, e.g. keep sentences short and simple and don't use jargon; write or draw ideas on paper for them. Check their understanding by asking them to tell you in their own words or way what you have just told them. Information and education on depression should be made available to staff and carers in order for them to provide appropriate and ongoing support.

What isn't supportive

- There's no point in just telling someone with depression to get better as they cannot "snap out of it" or "get over it".
- Do not be hostile or sarcastic when their responses are not what you usually expect of them. Rather, accept these responses as the best the person had to offer at that time.
- Do not adopt an over-involved or over – protective attitude towards someone who is depressed. This can be difficult for those who are already supporting a person with an intellectual disability because they are already involved in so many other aspects of the person's life.
- Do not nag the person to try to get them to do what they normally would.
- Do not trivialise the person's experiences by pressuring then to "put a smile on their face", to "get their act together", or to "lighten up".
- Do not belittle or dismiss the person's feelings by attempting to say something positive like, "you don't seem that bad to me".
- Avoid speaking with a patronising tone of voice and do not use overly-compassionate looks of concern.
- Resist the urge to try to cure the person's depression or to come up with answers to their problems.

ACTION 4:
Encourage and support the person to get appropriate professional help.

Everybody feels down or sad at times, but it is important to be able to recognise when depression has become more than a temporary experience for someone and when to encourage and support that person to seek professional help. Professional help is warranted when depression lasts for weeks and affects a person's functioning in daily life. Many people with depressive disorders do not seek professional help. In Australia, only 59% of people who had a depressive disorder in the past year received professional help for their problem.[6] even when people do eventually seek help, they can wait for many years before doing so.[59] These delays can affect their long-term recovery. People with depressive disorders are more likely to seek help if someone close to them suggests it[42] or provides them with support to access it. Also, people can help a GP make a quicker diagnosis by telling the doctor directly about their psychological symptoms and that they may be suffering from depression.[60, 61]

Discuss options for seeking professional help

You should ask the person if they need help to manage how they are feeling. If they feel they do need help, discuss the options that they have for seeking help and encourage them to use these options. If the person does not know where to get help, offer to help them seek assistance. It is

important to encourage the person to get appropriated professional help and effective treatment as early as possible. If the person would like you to support hem by accompanying them to an appointment with a health professional, you must not take over completely; a person with depression needs to make their own decisions as much as possible. Depression is not always recognised by health professionals; it may take some time to get a diagnosis and find a healthcare provider with whom the person is able to establish a good relationship. You should encourage the person not to give up seeking appropriate professional help.

The person with an intellectual disability may need additional support to find this kind of help and to take advantage of what is available. These professionals will require good information about the person with an intellectual disability, so it is important to involve a support person who knows the person well.

You may need to stay with them longer or, if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access a professional. Pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.[21]

It is important to take with you to a professional appointment any information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

What if the person doesn't want help?

The person may not want to seek professional help. You should find out if there are specific reason why this is the case. For example, the person might be concerned about finances, or about not having a doctor they like, or they might be worried they will be sent to hospital or somewhere else, which has been a common experience of people with an intellectual disability. These reasons may be based on mistaken beliefs, a lack of information or difficultly understanding the information. You may be able to help the person overcome their worry about seeking help, by assisting them to gain further information, or presenting the information in a way that makes it easier to understand. If the person still doesn't want help after you have explored their reasons with them, let them know that if they change their mind in the future about seeking help they can contact you. You must respect the person's right not to seek help unless you believe they are at risk of harming themselves or others.

ACTION 5:
Encourage other supports

Other people who can help

Encourage the person to consider other supports available to them such as family, friends, case workers, disability workers and support groups. Some people who experience depression find it helpful to meet with other people who have had similar experiences. There is some evidence that these mutual groups can help with recovery from depression and anxiety.[62] Family and friends can also be an important source of support for a person who is depressed. Recovery from symptoms is quicker for people who feel supported by those around them.[63]

In looking to family and friends of a person with an intellectual disability for support, it is important to keep in mind that they may be under stress or 'burnt out' due to their burden of care.

People with mental illnesses who are hospitalised are less likely to receive flowers, get-well cards and other gifts which can lead them to have feelings of rejection. It is important that family and friends provide the same sort of support to an ill person with a mental illness as they would to a person with a physical disorder. Providing the same support hey would for a person who is physically ill can include sending get-well cards, flowers, phoning or visiting the person, and helping out if they cannot manage.[64]

Self-help strategies

Self-help strategies are frequently used by people with depression.[65] The person's ability and desire to use self- help strategies will depend on their interests and the severity of their depression. Therefore you should not be too forceful when trying to encourage the person to use self-help strategies.

The person with an intellectual disability may have few if any self-help strategies due to their reduced cognitive abilities, lack of experience & education. Disability-specific services may offer specialised education programs to assist people to learn self-help strategies and generalise these into their everyday life. It is useful to contact the state government disability service in your locality for information about what is available.
If the person with an intellectual disability does have some strategies, they may need a reminder as to what they are, and then additional support to put these into practice.

Self-help strategies may be useful in conjunction with other treatments and may be suitable for people with less severe depression. It is important that severe or long lasting depression be assessed by a health professional. Not all self-help strategies are suitable for all people, because of side-effects or interactions with other medical illnesses or treatments. It is a good idea to discuss the appropriateness of self-help strategies with an appropriate professional.

HELPFUL RESOURCES
for depression and suicidal thoughts

Screening for depression

Questionnaires to screen for depression are available on the internet. These are scored automatically and give feedback on whether a person is likely to have a depressive disorder. These may not be as appropriate for people with intellectual disability as for the general population due to issues such as access and their ability to complete them. Any questionnaire about the person should be undertaken with a support worker, friend or family who knows them well. The following three resources have been developed specifically for use by people providing support to someone with an intellectual disability.

Depression in Adults with an Intellectual Disability Checklist for Carers
http://www.cddh.monash.org/research/depression/

This is a checklist completed by carers, in particular paid support staff, on behalf of adults who are unable to report their own feelings or symptoms because of severe communication impairment. It provides carers with information that is needed by a medical practitioner to decide if an adult with an intellectual disability may be depressed or suffering from a related mental health problem or need referral to a mental health specialist or practitioner. Conditions of use and a request form for the checklist can be found at Centre for developmental Disabilities health Victoria.

The Mini PAS ADD
http://www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=746

The Mini PAS-ADD system is a set of assessment tools for undertaking mental health assessments with people with learning disabilities. It is designed to provide a smooth, reliable flow of information on psychiatric symptoms from all those involved in an individual's care, including family members, support staff and care staff.

Reiss Screen
http://www.reiss-screen.com/shortform.htm

This test screens for mental health problems (dual diagnosis) in persons with intellectual disability by interviewing carers, teachers, work, supervisors, or parents.

Websites

***beyondblue*: the national depression initiative**
http://www.beyongblue.org.au/

This website provides questionnaires to allow self-assessment of anxiety and depression; information sheets on depression and anxiety disorders; and a list of doctors and mental health practitioners with an interest in treating depression. *beyondblue* also has a 24-hour helpline which gives information and referral to services for depression and anxiety. There is also a directory of e-mental health services and therapies.

BluePages
http://blupages.anu.edu.au/

This website provides: questionnaires to allow self-assessment of anxiety and depression; information on medical, psychological and alternative treatments for depression; resources for someone who is depressed; an on-line virtual support group; a downloadable relaxation tape; and a link to a site providing cognitive behaviour therapy. The BluePages site has been evaluated in a scientific trial and found to be effective in relieving depression symptoms if people work through it systematically.[66]

Living life to the Full
http://www.livinglifetothefull.com/

This is a Scottish website providing free cognitive behaviour therapy online.

MoodGYM
http://moodgym.anu.edu.au

This cognitive behaviour therapy website has been evaluated in a scientific trial and found to be effective in relieving depression symptoms if people work through it systematically.[66] This site teaches people to use ways of thinking which will help prevent depression.

National Institute of Mental Health (NIMH)
www.nimh.nih.gov

This US government site gives a wealth of excellent, up-to-date information on depression and suicide in the form of downloadable booklets and fact sheets.

Centre for Developmental Disability Health Victoria
http://www.cddh.monash.org/index.html

Has a link to a depression checklist for intellectual disability that carers can complete and take to a GP appointment.

Books

Burns DD (1999). *Feeling good: the new mood therapy (revised edition).* Quill Publishers, New York, NY, USA
This self-help book is based on cognitive behaviour therapy. Using the book in a systematic way has been found to be effective in research studies.[67]

Ellis TE (1996) *Choosing to live: How to defeat suicide through cognitive therapy.* New harbinger, Oakland, CA, USA.
Using non-judgemental language and cognitive therapy approached, this book is a useful guide to people who experience suicidal thoughts.

Johnstone M, Johnstone A (2008). *Living with a black dog: how to take care of someone with depression while looking after yourself.* Pan Macmillan Australia, Sydney, NSW, Australia.
This is another insightful self-help picture book for carers.

Jorm AF, Allen NB, Morgan AJ, Purcell R. (2009) *A guide to what works for depression. beyondblue:* Melbourne, Vic, Australia
This booklet looks at what the scientific evidence has to say about a wide range of treatment for depression. It is designed to help consumers make informed choices when seeking treatment. It is available for free from beyondblue.

Tanner S, Ball J (2001). *Beating the blues-a self-help approach to overcoming depression.* Sydney. NSW, Australia.
This is an Australian self-help book based on cognitive behaviour therapy.

Help Lines

Lifeline 24-Hour Counselling
13 11 14
Lifeline has trained volunteer counsellors available 24 hours a day, 7 days a week, for the cost of a local call.
http://www.lifeline.org.au

Kids Help Line
1800 55 1800
This telephone, web-based and email counselling service is available 24 hours a day, 7 days a week, for young people aged up to 25 years. It is free from a landline, but there will be a charge if a call is made from a mobile phone
http://www.kidshelp.com.au

Mensline Australia
1300 78 99 78
This is a telephone counselling service available 24 hours, 7 days a week, for men with relationship or family concerns.
www.menslineaus.org.au

Suicide Call Back Service
1300 659 467
This is a telephone counselling service available 24 hours a day, 7 days a week for people who are suicidal.
www.suicidecallbackservice.org.au

Mental Health Crisis Numbers

ACT:
Mental Health Triage Service, 24hrs, 7 days
1800 629 354 or 02 6205 1065

NSW:
Ring nearest hospital

NT:
Darwin Top End Mental Health Services
08 8999 4988

QLD:
Call Emergency Services 000 or
Lifeline 13 11 14

SA:
Crisis Team 13 14 65

TAS:
03 6233 2388 or 1800 332 388
(9am – 11pm) or nearest hospital

VIC:
Suicide Helpline Victoria 1300 651 251 or
ring nearest hospital which will contact nearest crisis team

WA:
Crisis team 1800 676 822

Mental Heath Emergency Response Line
1300 555 788

Support groups

Find out more about support groups anywhere in Australia, see the BluePages website at:
http://bluepages.anu.edu.au/help_and_resources/types-of-helo/support-group/

2.2 ANXIETY DISORDERS

Swirly Man

2.2 Anxiety

What is anxiety?

Everybody experiences **anxiety** at some time. When people describe their anxiety, they may use terms such as: anxious, stressed, uptight, nervous, frazzled, worried, tense or hassled. Although anxiety is an unpleasant state, it can be quite useful in helping a person to avoid dangerous situations and motivate the solving everyday problems. Anxiety can vary in severity from mild uneasiness through to a terrifying panic attack. Anxiety can also vary in how long it lasts, from a few moments to many years. Anxiety can show in a variety of ways: physical, psychological and behavioural, as shown in the box below.

An anxiety disorder differs from normal anxiety in the following ways.

- it is more severe
- it is long lasting
- it interferes with the person's work or relationships.

Anxiety disorders affect 14.4% of Australians aged 16-85 years in a given year, 17.9% of females and 10.8% of males.[39]

Anxiety disorders are more common in females than males. The median age of onset is 15 years,[15] which means that half the people who will ever have an anxiety disorder will have onset by this age. Anxiety disorders often co-occur with depression and substance use disorder.[39]

For people with an intellectual disability, this prevalence has been reported to be as high as 27%.[37]
Anxiety and stress disorders are often overlooked in people with an intellectual disability, mainly due to communication difficulties. In those with more severe or profound intellectual disability characteristics of these disorders are often misdiagnosed as challenging behaviour.[40]

There are several conditions associated with intellectual disability in which individuals may display some symptoms of anxiety, e.g. Autism Spectrum Disorder, Epilepsy, Williams Syndrome. Anxiety here is usually directly related to the condition and not a separate anxiety disorder. Even so, people with these conditions may still develop anxiety disorders. The first aid strategies and treatments mentioned here are appropriate regardless of the origins of the anxiety.[13,14,37]

Signs and symptoms of Anxiety
Symptoms of anxiety will affect how someone feels, how they think, how they behave and their physical wellbeing. Some examples are listed below:

Emotions
Unrealistic or excessive fear, irritability, impatience, anger, confusion, feeling on edge, nervousness, depressed mood. A person with an intellectual disability may be more likely to report their inner experience by talking about physical sensations due to difficulties describing their emotional states.

Thoughts
Lots of worry about past or future events, mind racing or going blank, poorer concentration and memory, trouble making decisions, vivid dreams.

Behaviour
Avoiding situations or people, obsessive or compulsive behaviour, distress in social situations, increased use of alcohol or other drugs. For people with an intellectual disability symptoms may also include self injurious behaviour, aggressive behaviour, disruptive or defiant behaviour, self soothing behaviours (e.g. rocking, eating, or bathing) 'clingy' or over-demanding behaviour, withdrawal, seeming to 'freeze', overactivity, repetitive questioning and sexual dysfunction[14,9,22,10]

Physical
Pounding heart, chest pain, rapid heartbeat, blushing, rapid shortness of breath, dizziness, headache, sweating, tingling and numbness, choking, dry mouth (increased drinking), stomach pains, nausea, vomiting, and diarrhoea, muscle aches and pains (especially neck, shoulders and back), restlessness, tremors and shaking, have difficulty sleeping.
When reporting physical symptoms, people with an intellectual disability may not use medical terms and be less specific about the location of their symptoms. Some of their physical health concerns may also be unfounded.

It is important when considering the symptoms of various anxiety disorders to do so in the context of the developmental level of the person with an intellectual disability, particularly their cognitive and emotional capacity.[66] People with an intellectual disability often have reduced insight into their emotions and feelings as well as a reduced ability to verbally communicate these clearly. It therefore may be more useful to rely more on observable behaviours rather than self-reports.[13] Behavioural signs of anxiety disorder are often mis-diagnosed as due to one of the more readily recognised disorders. e.g schizophrenia.

Physical illness and the effects of medication may be an underlying cause of an anxiety disorder and should be ruled out first if possible.[14]

The greater the level of intellectual disability, the more likely it is that anxiety will be demonstrated through the person's behaviour. However not all challenging behaviour is due to anxiety disorder. There may be other environmental factors (e.g. disliking another person in the environment, or not wanting to carry out a particular task) that are the reason for challenging behaviour.[14]

Types of anxiety disorders

There are many different types of anxiety disorders.[2] The main ones are generalised anxiety disorder, panic disorder and agoraphobia, phobic disorders, post-traumatic stress disorder and obsessive-compulsive disorder. It is not unusual for a person to have more than one of these anxiety disorders. The table below shows how common each of these is.

wrong or ones; inability to cope) accompanied by multiple physical and psychological symptoms of anxiety or tension occurring more days than not, for a least six months. People with generalised anxiety disorder worry excessively about money, health, family and work/day options, even when there are no signs of trouble. For people with an intellectual disability this may also include friendships, relationships with staff and carers. The anxiety appears difficult to control. Other characteristics can include an intolerance of uncertainty, belief that worry is a helpful way to deal with problems and poor problem-solving. Generalised anxiety disorder can make it difficult for people to concentrate at school or work, function at home and generally get on with their lives.

The rate for GAD is similar if not higher than in the general population.[13,14] Phenylketonuria (PKU) and William's syndrome have been associated with GAD in the intellectually disabled population.

Panic disorder and agoraphobia

Some people have short periods of extreme anxiety called a panic attack. A **panic attack** is a sudden onset of intense apprehension, fear or terror. These attacks can begin suddenly and develop rapidly. This intense fear is inappropriate for the circumstances in which it is occurring. Other symptoms, many of which can appear similar to those of a heart attack, can include racing heart, sweating, shortness of breath, chest pain, dizziness, feeling detached from oneself and fears of losing control. Once a person has one of these attacks, they often fear another attack and may avoid places where attacks have occurred. The person may avoid exercise or other activities that may produce physical sensations similar to those of a panic attack.

Percentage of Australian aged 16-85 with anxiety disorders in any one year[6]

Type of anxiety disorder	Males	Females	All
Post-traumatic stress disorder	4.6%	8.3%	6.4%
Social phobia	3.8%	5.7%	4.7%
Agoraphobia	2.1%	3.5%	2.8%
Generalised anxiety disorder	2.0%	3.5%	2.7%
Panic disorder	2.3%	2.9%	2.6%
Obsessive-compulsive disorder	1.6%	2.2%	1.9%
Any anxiety disorder	**10.8%**	**17.9%**	**14.4%**

Generalised Anxiety Disorder (GAD)

Some people experience long term anxiety across a whole range of situations and this interferes with their life. These people have generalised anxiety disorder. The main symptoms of generalised anxiety disorder are overwhelming, unfounded anxiety and worry (about things that may go

attack and a panic disorder. Having a panic attack does not necessarily mean that a person will develop panic disorder. A person with **panic disorder** experiences recurring panic attacks and, for at least one month, is persistently worried about possible consequences of panic attacks, such as fear of losing control or having a heart attack. Some people may develop panic disorder

after only a few panic attacks, while others may experience many panic attacks without developing a panic disorder. Some people with panic disorder go onto having agoraphobia (described below) where they avoid places where they fear they may have a panic attack.

Avoidance of situations or activities associated with some of the anxiety disorders may be limited or hampered in people with an intellectual disability. This can be due to support arrangements, level of disability and lack of choice. This may then result in their use of aggressive, non-compliant or self-injurious behaviours.

Agoraphobia involves avoidance of situations where the person fears they may have a panic attack. The focus of their anxiety is that it will be difficult or embarrassing to get away from the place if a panic attack occurs, or that there will be no one present who can help. This leads them to avoid certain situations for fear of a panic attack occurring. Some may avoid only a few situations or places, for example crowds, enclosed places such as shopping malls, or driving. Others may avoid leaving their homes altogether.

Agoraphobia is thought by many to mean a fear of open spaces or a fear of leaving the house. While these symptoms may occur with agoraphobic, the person cannot be said to have agoraphobia unless they have a fear of panic attacks.

Phobic disorders

A person with a phobia avoids or restricts activities because of fear. This fear appears persistent, excessive and unreasonable. They may have an unreasonably strong fear of specific places or events and often avoid these situations completely.

There seems to be uncertainty about the true extent of *phobias* in people with intellectual disability. This may in part be due to the difficulty of diagnosing this condition in this population. Adults with an intellectual disability appear to have similar rates of phobias as children without an intellectual disability. This is possibly due to the fact that they share some common lifestyle characteristics such as;

- lack of control over their life,
- a feeling of powerlessness,
- not having the means to avoid the source of their phobia,
- being more likely to experience failure due to lack of knowledge or skills,
- lack of insight, and underdeveloped problem solving skills.[37]

Social phobia is the fear of any situation where public scrutiny may occur, usually with the fear of behaving in a way that is embarrassing or humiliating. They key fear is that others will think badly of the person. Social phobia often develops in shy children as they move into adolescence. Commonly feared situations include speaking or eating in public, dating and social events.

People with ASD (Autism Spectrum Disorder) often display symptoms of social phobia as part of their disorder. Fragile X syndrome is also often associated with social anxiety.

Specific phobias are phobias of specific objects or situations. The most common fears are of spiders, insects, mice, snakes and heights. Other feared objects or situations include an animal, blood, injections, storms, driving, flying, or enclosed places. Because they only involve specific situations or objects, these phobias are usually less disabling than agoraphobia and social phobia.

It has been reported that adults with an intellectual disability have a higher rate of specific phobias (e.g. spiders, heights, specific situations) than the general population.[14]

Post-traumatic stress disorder (PTSD)

Post-traumatic stress disorder can occur after a person experiences what they perceive to be a traumatic event. What is perceived as traumatic will vary from person to person. Common examples of traumas that many people find traumatic include involvement in war, accidents, assault (including physical or sexual assault, mugging or robbery, or family violence), and witnessing something terrible happen. Mass traumatic events include terrorist attacks, mass shootings, warfare and severe weather events (cyclone, tsunami and bushfire).

It is thought that people with an intellectual disability, due to increased vulnerability (associated with greater dependence, living in unsuitable and sometimes stressful environments), are at a greater risk for experiencing repeated traumatisation and hence PTSD.[42]

A major symptom is re-experiencing the trauma. This may be in the form of recurrent dreams of the event, flashbacks, intrusive memories or unrest in situations that bring back memories of the original trauma. In people with an intellectual disability, flashbacks and memories may be more vague or distorted or may be re-experienced and reported as a 'recent event'.[68] Because of a reduced ability to communicate about their symptoms, it may appear that the person with an intellectual

disability who is experiencing a stress reaction is having hallucinations.

There is avoidance behaviour, such as persistent avoidance of things associated with the event, emotional numbing, which may continue for months or years, or reduced interest in others and the outside world. In an attempt to avoid certain situations or stimuli, the person with an intellectual disability may display aggressive, escape or non-compliant behaviours.[68] Also persistent symptoms of increased emotional distress occur (constant watchfulness, irritability, jumpiness, being easily startled, outburst of rage, insomnia).

People with an intellectual disability may express their fear by screaming, crying, nightmares, cringing when approached by people, hiding, and wearing several layers of clothing while sleeping. They may also show persistent signs of increased arousal (hyper-vigilance, irritability, exaggerated startle response, outbursts of rage, insomnia, enuresis, encopresis).

There is little information about prevalence of PTSD for people with an intellectual disability. However, the literature suggests that when they are exposed to trauma, PTSD develops at a rate comparable to the general population.[68] Limited recognition of PTSD in people with intellectual disability may mean that its symptoms are attributed to other psychiatric diagnosis (e.g. schizophrenia). Diagnosis of PTSD in those who have limited ability to describe their thoughts, feelings and mood is difficult.[68]

It is common for people to feel greatly distressed immediately following a traumatic event. This is called **acute stress reaction** and the person usually gets over it within a month. If their distress lasts longer than a month, they may have post-traumatic stress disorder. Only some people who experience acute stress disorder will go on to develop a mental illness such as post-traumatic stress disorder or depression. A person is more likely to develop post-traumatic stress disorder if their response to the event involves fear helplessness or horror.

Obsessive-compulsive disorder (OCD)

This type of anxiety disorder is the least common but is a very disabling condition. Rates of OCD range from 1%-3.5% in the intellectually disabled population[14] as compared with 1-2% for the non intellectually disabled population[37]. OCD begins in adolescence and may be a lifelong illness. Obsessive thoughts and compulsive behaviours accompany feelings of anxiety. Obsessive thoughts are recurrent thoughts, impulses and images that are experienced as intrusive, unwanted an inappropriate and cause marked anxiety. Most obsessive thoughts are about fear of contamination, symmetry and exactness, safety, sexual impulses, aggressive impulses and religious occupation. In the person with an intellectual disability these are less prominent and compulsions alone may be the predominant symptom.[17]

Compulsive behaviours are repetitive behaviours or mental acts that the person feels driven to perform in response to an obsession in order to reduce anxiety. Common compulsions include the washing, checking, repeating, ordering, counting, hoarding, or touching thins over and over.

It can be difficult to distinguish between compulsions and stereotypic behaviour in a person with an intellectual disability. Typically individuals engaged in stereotypic behaviour do not seem to want to stop the behaviour or be distressed by it. In contrast, people with compulsive behaviours may try to resist performing the behaviours, which cause distress.[12]
Five types of compulsion have been identified as common in people with intellectual disability:[12]

- *Ordering* compulsions (e.g. arranging objects/people into certain spots).
- *Completeness/incompleteness* compulsions (e.g. closing doors, dressing and undressing).
- *Cleaning/tidiness* compulsions (e.g. repeatedly cleaning one body part, must take out the garbage when full).
- *Checking/touching* compulsions (e.g. touches items repeatedly)
- *Grooming* compulsions (e.g. checks self in mirror excessively).

Ritualistic/compulsive behaviours themselves are common in adults with intellectual disability; however their cause is not always apparent. Repetitive thoughts and ritualistic behaviours associated with OCD have sometimes been misdiagnosed as indicating autism.[23] Ritualistic/compulsive behaviours can also commonly seen in people with Cornelia de Lange, Rubenstein-Taybi and Prader-Willi syndromes.[13]

Due to the inability of many people with an intellectual disability to identify the thoughts and feelings associated with their need to perform behaviours, it becomes important to observe for behavioural indicators of OCD such as, aggression when rituals are interrupted, tense facial expression, clingy behaviour, agitated outbursts, behaviours that resemble hyperactivity.[37] The ability to identify rituals and thoughts as irrational and dysfunctional may be lacking for those with an intellectual disability. This however should not rule out OCD as an explanation for the person's symptoms.[12]

Mixed anxiety and depression and substance misuse

Many people with anxiety problems do not fit neatly into a particular type of anxiety disorder. It is common for people to have some features of several anxiety disorders. A high level of anxiety over a long period will often lead to depression, so that many people have a mixture of anxiety and depression.

It has been estimated that 66% of people with an intellectual disability and OCD will also experience major depression at some point in their lives.[37] The literature reports that the rate of mixed anxiety and depression for people with intellectual disability is about the same as for the general population.[14]

Substance misuse frequently occurs with anxiety disorders, as a form of self-medication to help cope. However, alcohol and other drug misuse can lead to increased anxiety.[69]

Risk factors for anxiety disorders

Anxiety is mostly caused by perceived threats in the environment, but some people are more likely than others to react with anxiety when they are threatened. People most at risk of developing an anxiety disorder are those who:[70, 71]

- Have a more sensitive emotional nature and who tend to see the world as threatening
- Have a history of anxiety in childhood or adolescence, including marked shyness
- Are female
- Abuse alcohol
- Experience a traumatic event
- People with an intellectual disability. They often have difficulty with change and new situations and have at times a heightened sensitivity to factors in the environment that others may not detect. They also tend to have few or ineffective coping strategies and reduced problem solving abilities.

There are some family factors that increase risk for anxiety disorders:

- A difficult childhood (for example, experiencing physical, emotional, or sexual abuse, neglect, or over-strictness)
- A family background which involves poverty or a lack of job skills
- A family history of anxiety disorder
- Parental alcohol problems
- Separation and divorce.

Anxiety symptoms can also result from:

- Some medical conditions such as hyperthyroidism, arrhythmias, respiratory conditions such as chronic obstructive pulmonary disorder, metabolic conditions such as vitamin B12 deficiency[2]
- Side effects of certain prescription and non-prescription medications
- Intoxication with alcohol, amphetamines, caffeine, cannabis, cocaine, hallucinogens, and inhalants
- Withdrawal from alcohol, cocaine, sedatives and anti-anxiety medications.

Some people develop ways of reducing their anxiety that cause further problems. For example, people with phobias avoid anxiety-provoking situations. This avoidance reduces their anxiety in the short term but can limit their lives in significant ways. Similarly, people with compulsions reduce their anxiety by repetitive acts such as washing hands. The compulsions then become problems in themselves. Some people will use drugs and alcohol to cope with anxiety, which can increase anxiety in the long term.

People with an intellectual disability may develop aggressive or self-harm behaviours in order to try and cope with or to communicate their anxiety.

Interventions for anxiety disorders

Professionals who can help

A variety of health professionals can provide help to the person with anxiety disorders:

- GPs
- Psychologists
- Counsellors
- Psychiatrists
- Allied health professionals such as occupational therapists, social workers and mental health nurses.

More information about these professionals can be found in Section1.1 *Mental Health Problems and Intellectual Disability in Australia*

If the person is uncertain about what to do, encourage and support the person to consult a GP first, as they can check if there is an underlying physical health problem causing this anxiety and refer the person to the appropriate specialist for help.

Treatments available for anxiety disorders

Research shows that a wide range of treatments can help with anxiety disorders.[72]

Psychological therapies.

- ***Cognitive behaviour therapy*** is the best all round treatment for anxiety disorders. It involves working with a therapist to look at

patterns of thinking (cognition) and acting (behaviour) that are making the person more likely to have problems with anxiety, or are keeping them from improving once they become anxious. Once these patterns are recognised, then the person can make changes to replace these patterns with new ones that reduce anxiety and improve coping. The degree to which the type of CBT needs to be adapted and the benefits of it will depend on the person's level of disability, the problem it is being used to address and the professional's understanding of intellectual disability.

- ***Behaviour therapy (also known as exposure therapy)*** is often a component of cognitive behaviour therapy. It involves exposing the person to the things that make them anxious. The person might be exposed to feared situations in real life or in imagination, usually in a gradual way. This type of therapy teaches the person that their fear will reduce without the need to avoid or escape the situation, and that their fears about the situation often do not come true or are not as bad as they thought.

Medical treatments

Scientific evidence supports the effectiveness of a number of medications:

- ***Antidepressant medications*** are effective for most anxiety disorders as well as for depression.

- ***Anti-anxiety medications*** such as benzodiazepines are also effective in reducing anxiety, but should be restricted to short-term use only because of concerns about possible side effect of dependency, sedation, rebound anxiety and memory impairment.

Medications should be used where possible in combination with other interventions that provide the person with skills to manage their mental illness. Medications should be frequently reviewed by a GP or psychiatrist.

Lifestyle and complementary therapies

Those with some scientific evidence for effectiveness in helping people with anxiety disorders include:

- ***Relaxation training*** involves learning to relax by tensing or relaxing specific groups of muscles, or by thinking of relaxing scenes or places. Recorded instructions are available for free on the internet or can be bough on CDs (see resources at the end of this chapter). Relaxation training is most useful when learned under the guidance of a health professional. There are various adapted relaxation training programs commonly used with people who have an intellectual disability without mental health issues to address skill deficits in areas such as coping and waiting. (see resources at the end of this chapter)

- ***Self-help books*** which are based on cognitive behaviour therapy or behaviour therapy (see resources at the end of this chapter). These are most useful when used under the guidance of a health professional.

- ***Computerised therapy*** which is self-help treatment delivered over the internet or on a computer. Some are available for free (see resources at the end of this chapter). These are most useful when used under the guidance of a health professional.

In relation to self-help books and computerised therapy, people with an intellectual disability would need some level of literacy to access these as well perhaps as assistance from family, a case worker or disability worker.

There are a number of other complementary therapies which have weaker evidence as effective for some types of anxiety disorders. For further information see a *Guide to What Works for Anxiety Disorders* in the resources section of this chapter.

Importance of early intervention for anxiety

It is important that anxiety disorders are recognised and treated early because they can have a major impact on a person's subsequent life. Anxiety disorders often develop in childhood and adolescence and, if they are not treated, the person is more likely to have a range of adverse outcomes later in life such as depression, alcohol dependence, drug dependence, suicide attempts, lowered education achievement and early parenthood.[71] Because of these long-term consequences, it is very important that anxiety disorders are recognised early and people get appropriate professional help.

Crises associated with anxiety

Crises that may be associated with anxiety are:

- The person goes into a **panic attack**
- The person has experienced a **traumatic event**
- The person has **suicidal thoughts and behaviours**
- The person is engaging in **non-suicidal self-injury**

Panic attack

More than one in four people have a panic attack at some time in their lives.[73] Few go on to have repeated attacks, and fewer still go on to develop panic disorder or agoraphobia. Although anyone can have a panic attack, people with anxiety disorders are more prone to them.

Traumatic event

A traumatic event is any event which is perceived to be traumatic by the person who experiences it. Most people who experience a traumatic event do not develop a mental illness. Others experience symptoms of severe stress and may go on to develop acute stress disorder, posttraumatic stress disorder, another anxiety disorder or depression. People at most risk of developing mental illness after a traumatic event are those who are prone to depression or anxiety before the event and those who feel horror or powerlessness during the event. As stated in the previous chapter, people with an intellectual disability are at a greater risk than the general population of developing depression thereby making them more prone to developing a mental illness following a traumatic event.

Suicidal thoughts and behaviours

Extreme levels of anxiety are the most obvious crisis seen in people with anxiety disorders. However, there is also the possibility of suicidal thoughts. The risk of suicide in people with anxiety disorders is not at high as for some other mental illnesses.[74] However, the risk increases if the person also has a depressive or substance use disorder. Of people who have had an anxiety disorder in the past 12 months, approximately 2% attempt suicide.[54] Therefore, in any interaction with a person with an anxiety disorder, be alert to any warning signs of suicide.

Suicidal thinking and high risk-taking behaviour in those with an intellectual disability should always be investigated. The method chosen by a person with an intellectual disability may not have any lethal potential, but may have been chosen because the person believed it would be fatal, so the intent is still there.[12]

Non-suicidal self-injury

Anxiety disorders greatly increase the risk for non-suicidal self-injury.[55] non-suicidal self-injury may be a coping mechanism for feelings of unbearable anxiety.

People with an intellectual disability, especially those with more significant levels, often engage in self-injurious behaviour (SIB). Very commonly, SIB is a result of the person's inability to communicate their boredom, loneliness, anger, or physical pain to others.

Mental Health First Aid Action Plan for People with an Intellectual Disability and Anxiety

1. **Approach the person , assess and assist with any crisis**
2. **Listen non-judgementally**
3. **Give support and information**
4. **Encourage and support the person to get appropriate professional help.**
   The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered
5. **Encourage other supports.**
   The person with an intellectual disability may need assistance to do this

ACTION 1:
Approach the person, assess and assist with any crisis

How to approach

The approach that is helpful to someone with troublesome anxiety is very similar to that for someone experiencing depression – see Section 2 *Depression.* The key points are:

- Approach the person about your concerns about their anxiety
- Find a suitable time and space where you both feel comfortable
- If the person does not initiate a conversation with you about how they are feeling, you should say something to them
- Respect the person's privacy and confidentiality.

When asking questions of a person with an intellectual disability it is important to:

- Communicate in a way that will assist them to understand e.g. by using visual aids,
- Check they have understood what you are asking by getting them to tell you in their own words, pictures, signs what they think you are asking them.
- Avoid asking leading questions.
- Be aware that people with an intellectual disability will often answer in the affirmative in order to please or appear capable so check that what they say is what they really mean.

As you talk with the person, be on the lookout for any indications that the person may be in crisis.

*If you have concerns that the person may be having a **panic attack**, find out how to **assess** and **assist** this person in Section 3.3 First Aid for Panic Attacks.*

*If the person has experiences a **traumatic event**, find out how to **assess** and **assist** this person in Section 3.4 First Aid Following a Traumatic Event.*

*If you have concerns that the person may be having **suicidal thoughts**, find out how to **assess** and **assist** this person in Section 3.1 First Aid for Suicidal thoughts and Behaviours.*

*If you have concerns that the person may be engaging in **non-suicidal self-injury**, find out how to **assess** and **assist** in Section 3.2 First Aid for Non-suicidal Self-injury.*

If you have no concerns that the person is in crisis, you can ask them about how they are feeling and how long they have been feeling that way and move on to ACTION 2.

ACTION 2:
Listen non-judgementally

See Action 2 in Section 2.1 *Depression* for more tips on non-judgemental listening. Some main points to remember are:

- Engage the person in discussing how they are feeling and listen carefully to what they say. People with an intellectual disability often

have trouble recognising their emotions and expressing them verbally. You may need to give them additional time to think and respond, as well as offer alternative means for them to tell you how or what they are feeling (e.g, pictorially, role play)
- Do not express any negative judgements about the person's character or situation.
- Be aware of your body language, including posture, eye contact, and physical position in relation to the other person. Remember that some people (e.g. those with Autism) may be uncomfortable with direct eye contact.
- To ensure you understand what the person says, reflect back what you hear and ask clarifying questions.
- When listening to a person with an intellectual disability, you may need to use more checking questions and paraphrasing to ensure that you have understood correctly. It is far better to ask the person to repeat what they said, or to say it in a different way, than to pretend that you have understood them or to assume that they have understood you.
- Allow silences; be patient, do not interrupt the person, and use only minimal prompts such as "I see' and "Ah". If the person has an intellectual disability, they may need more time to use whatever means they are using to express themselves clearly.
- Do not give flippant or unhelpful advice, such as "pull yourself together". The person doesn't have control over their behaviour or mood at this time. You are there to support, not to judge or punish.
- Avoid confrontation unless necessary to prevent harmful acts.

ACTION 3:
Give support and information

See Action 3 in Section 2.1 *Depression* for more advice about giving support and information. The support and information that is helpful to someone with troublesome anxiety is very similar to that given to someone experiencing depression. You can support he person in the following ways:

- Treat the person with respect and dignity
- Do not blame the person for their illness
- Have realistic expectations for the person
- Offer consistent emotional support and understanding
- Give the person hope for recovery
- Provide practical help
- Offer information

Information and education on anxiety disorders should be made available to staff and carers so they can provide appropriate and ongoing support.

For people with an intellectual disability, information and reassurance needs to be given in a way that will promote understanding, e.g. keep sentences short and simple and don't use jargon; write or draw ideas on paper for them. Check their understanding by asking them to tell you in their own words, or other appropriate way what you have just told them.

What isn't supportive

It is important for the first aider to know that recovery from anxiety disorders required facing situations which are anxiety-provoking. Avoiding such situations can slow recovery and make anxiety worse. Sometimes, family and friends can think they are being supportive by facilitating the person's avoidance of anxiety-provoking situations, but can inadvertently slow down the recovery process.

Other actions that are also not supportive include: dismissing their fears as trivial, for example, by saying, "that is nothing to be afraid of", telling them "toughen up" or "don't be so weak" and speaking in a patronising tone of voice.

ACTION 4:
Encourage and support the person to get appropriate professional help

Many people with anxiety disorders do not realise there are treatments that can help them have a better life. In Australia, only 38% of the people who had an anxiety disorder in the past year received professional help for their problem.[6] People can sometimes delay seeking help for many years. Delays of 10 years of more are not unusual.[59] These delays can cause serious consequences in the person's life, limiting social and occupational opportunities and increasing the risk for depression, and drug and alcohol problems.

Discuss options for seeking professional help

Ask the person if they need help to manage how they are feeling. If they do need help, then respond as follows:

- Discuss the appropriate professional help and effective treatment options that they have for seeking help and encourage and support the person to use these options
- Offer to help them seek out these options
- Encourage the person not to give up seeking appropriate professional help.

The person with an intellectual disability may need additional support to link them with appropriate professional help. These professionals will require good information about the person with an

intellectual disability so, it is important to involve a support person who knows the person well.

You may need to stay with them longer, or if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access a professional. Pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.[21]

It is important to take with you to a professional appointment any information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

What if the person doesn't want help?

The person may not want to seek professional help. You should find out if there are specific reasons why this is the case. For example, the person might be concerned about finances, or about not having a doctor they like. You may be able to help the person overcome their worry about seeking help. If the person still doesn't want help after you have explored their reasons with them, let them know that if they change their mind in the future about seeking help they can contact you. You must respect the person's right not to seek help unless you believe that they are at risk of harming themselves or others.

ACTION 5:
Encourage other supports

Other people who can help

Encourage the person to consider other support available to them, such as family, friends, case workers, disability workers, and support groups. There is some evidence that mutual support groups may be helpful for people with depression and anxiety problems.[62] In looking to family and friends of the person with an intellectual disability for support, it is important to keep in mind that they may be under stress or 'burnt out' due to their burden of care.

Self-help strategies

People who are troubled by anxiety frequently use self-help strategies. The person's ability and desire to sue self-help strategies will depend on their interests and the severity of their symptoms. Therefore you should not be too forceful when trying to encourage the person to use self-help strategies.

People wishing to use self-help strategies should discuss these with a professional. Some self-help strategies may not be suitable for every person with an anxiety disorder and people with more severe anxiety disorders may need to use self-help strategies in conjunction with medical or psychological treatments.

The person with an intellectual disability may have few if any self-help strategies due to their reduced cognitive abilities, lack of experience and education. Disability-specific services may offer specialised education programs to assist people to learn self-help strategies and generalise them into their every day life. It is useful to contact the state government disability service in your locality for information about what is available.

If the person with an intellectual disability does have some strategies, they may need a reminder as to what they are, and then additional support to put these into practice.

HELPFUL RESOURCES
for Anxiety

Screening for anxiety disorders.

Questionnaires to screen for anxiety disorders are available on the internet. These are scored automatically and give feedback on whether a person is likely to have an anxiety disorder. These may not be as appropriate for people with intellectual disability as for the general population due to issues such as access and their ability to complete them. Any questionnaire about the person should be undertaken with a support worker, friend or family who knows them well.

Useful sites are:

beyondblue
(http://www.beyongblue.org.au/)

Patient UK
(http://www.patient.co.uk/doctor/Generalised-Anxiety-Disorder-Assessment-(GAD-7).htm)

The Mini PAS ADD
http://www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Product=746

The Mini PAS-ADD system is a set of set of assessment tools for undertaking mental health assessments with people with learning disabilities. It is designed to provide a smooth, reliable flow of information on psychiatric symptoms from all those involved in an individual's care, including family members, support staff and care staff.

Reiss Screen
http://www.reiss-screen.com/shortform.htm

This test screens for mental health problems (dual diagnosis) in persons with intellectual disability by interviewing carers, teachers, work, supervisors, or parents.

Websites

***Beyondblue:* the national depression initiative**
http://www.beyondblue.org.au/
This website provides: questionnaires to allow self-assessment of anxiety and depression; information sheets on depression and anxiety disorders; and a list of doctors and mental health practitioners with an interest in treating mental illness. *beyondblue* also has a 24-hour helpline which gives information and referral to services for depression and anxiety. There is also a directory of e-mental health services and therapies.

National Institute of Mental Health
http://www.nimh.nih.gov/

This is a US government website which has a wealth of information on anxiety disorders.

Clinical Research Unit for Anxiety and Depression (CRUFAD)
http://www.crufad.com/

This unit is run by the University of New South Wales and St Vincent's Hospital, Sydney. CRUFAD also has a clinic providing cognitive behaviour therapy for anxiety disorders. Its website provides good information about self-help and treatments for various anxiety disorders.

e-couch
http://ecouch.anu.edu.au

The e-couch website comes from the Australian national University and is free of charge. It provides information about emotional problems (including depression and anxiety disorders) – what causes them, how to prevent them and how to treat them. It also provides computerised therapy designed to equip the user with strategies to improve anxiety and depression, along with a workbook to track progress and record experiences.

Anxiety Online
www.anxietyonline.org.au

Anxiety online is an internet-based virtual assessment and treatment clinic for Australians with anxiety disorders. This site provides information about anxiety disorders, free self-help programs and low-cost therapist-assisted programs.

Books
General Books

Bourne E (2005). *The anxiety and phobia workbook*. *(4th Edition)* New Harbinger Publications, Oakland CA. USA
This is an excellent self-help book based on cognitive behaviour therapy.

Marks I (2001). *Living with fear*. McGraw- Hill Education, Berkshire, England.
This book is also based on cognitive behaviour therapy. It includes a very useful chapter on self-help for fears and anxiety. Research has shown that people with phobias who follow the instructions in this chapter improve as much as people treated by a professional.[75]

Revealey N, Allen NB, Jorm AF, Morgan AJ, Purcell R (2010). *A Guide to What Works for Anxiety Disorders. Beyondblue:* Melbourne, VIC Australia.

This booklet looks at what the scientific evidence has to say about a wide range of treatments for anxiety disorders. It is designed to help consumers make informed choices when seeking treatment. It is available for free from *beyondblue.*

Cautela, J. R., & Groden, J. (1978). **Relaxation: A comprehensive manual for adults, children, and children with special needs**. Champaign, IL: Research Press. www.researchpress.com

This manual has sections on (1) self-relaxation techniques designed for adults, (2) methods for teaching relaxation to adults and older children, and (3) procedures for teaching relaxation to young children and children with developmental disabilities. The clear, concise text is supplemented by over 100 helpful illustrations.

Panic Books

Antony MM, McCabe R (2004). *10 simple solutions to panic: how to overcome panic attacks, calm physical symptoms, and reclaim your life.* New harbinger Publications, Oakland, CA, USA.
This small-format self-help book is based on CBT principles and may help people who experience panic attacks. The focus is on thinking realistically about future attacks rather than worrying about them.

Zuercher-White E (1998). *An end to panic: breakthrough techniques for overcoming panic disorder.* New Harbinger Publications, Oakland, CA, USA
This self-help workbook is based on CBT principles and may help people who experience panic attacks, panic disorder and agoraphobia.

Social anxiety books

Rapee RM (1998). *Overcoming shyness and social phobia*. Lifestyle Press, Killara NSW.
ISBN 0 9585453 08.
This Australian self-help book is based on cognitive behaviour therapy. Research has shown that people who work through the book systematically reduce their anxiety.[76]

Antony MM, Swinson RP (2000). *The shyness & social anxiety workbook: proven techniques for overcoming your fears.* New harbinger Publications, Oakland, CA, USA
This large-format self-help workbook uses the principles of CBT to help people overcome shyness and social phobia.

Stein MB, Walker JR (2001). *Triumph over shyness: Conquering shyness & social anxiety.* McGraw-Hill, New York, NY, USA.
This self-help book is co-published and endorsed by the Anxiety disorders Association of America. It may be useful for people with social phobia but also those who struggle with non-clinical shyness. A range of approaches are used.

Phobia books

The "I Can Do it" series of books describes cognitive behaviour therapy techniques for people work on specific phobias. They are published by New harbinger Publications, Oakland, CA, USA
Topics include: animal and insect phobias, medical phobias and fear of heights.

Post-traumatic stress disorder book

Williams MB, Piojula S (2002). *The PTSD workbook: simple, effective techniques for overcoming traumatic stress symptoms.* New harbinger Publications, Oakland CA, USA.
This self-help book draws on techniques and interventions used by PTSD experts to offer trauma survivors the most effective tools available to conquer their most distressing symptoms.

OCD books

Foa EB, Wilson R (2001) *Stop obsessing: how to overcome your obsessions and compulsions.* Revised. Bantam Books, New York, NY, USA.
A CBT-based self-help manual for overcoming OCD> Readers are encouraged to tailor a CBT program for themselves which will target their specific obsessions and compulsions. It also includes self-tests and case studies from the authors' significant clinical backgrounds.

The following four books are a set of self-help workbooks that focus on practical strategies for overcoming specific types of OCD. By selecting the workbook which focuses on the main compulsive symptom (checking, washing or hoarding) and then adding the manual no obsessions, an individual can create their own CBT program for overcoming OCD.

Neviroglu F, Bubrick J (2004). *Overcoming compulsive hoarding: why you save and how you can stop.* New harbinger Publications, Oakland, CA, USA.

Munford P (2004). *Overcoming compulsive washing: free your mind from OCD.* New harbinger Publications, Oakland, CA, USA

Munford P (2004). *Overcoming compulsive checking: free your mind from OCD.* New harbinger Publications, Oakland, CA, USA.

Purdon C, Clark DA (2005) *Overcoming obsessive thought: how to gain control of your OCD.* New Harbinger Publications, Oakland, CA, USA

Help Lines

Lifeline 24-Hour Counselling
13 11 14
Lifeline has trained volunteer counsellors available 24 hours a day for the cost of a local call.

Lifeline Information Service
1300 13 11 14 (Monday-Friday, 9am-5pm)
The service provides information and referral for people dealing with mental health issues, personally or as a family member or friend of someone with mental illness. This service also provides callers with information about relevant local services, as well as links to books and websites.

2.3 PSYCHOSIS

Golden Pond

2.3 Psychosis

What is psychosis?

Psychosis is a general term to describe a mental health problem in which a person has lost some contact with reality. There are severe disturbances in thinking, emotion and behaviour. Psychosis can severely disrupt a person's life. Relationships, work and other usual activities, and self-care can be difficult to initiate and/or maintain.

Psychotic disorders are less common than other mental illness. There are numerous disorders in which a person can experience psychosis, including schizophrenia, psychotic depression, bipolar disorder (which can involve psychotic depression or psychotic mania), schizoaffective disorder and drug-induced psychosis.

People usually experience psychosis in episodes. An episode can involve the following phases, which vary in length from person to person.[77]

- **Premorbid** (at risk phase) – the person does not experience any symptoms but has risk factors for developing psychosis.
- **Prodromal** (becoming unwell phase) - the person has some changes in their emotions, motivation, thinking and perception or behaviour as described in the box below.
- **Acute** (psychotic phase) – the person is unwell with psychotic symptoms such as delusions, hallucinations, disorganised thinking and reduction in ability to maintain social relationships, work or study.
- **Recovery** – this is an individual process there person goes through to attain a level of well-being.
- **Relapse** – the person may only have one episode in their life or may go on to have other episodes.

Common signs and symptoms when psychosis is developing[78]

Changes in emotion and motivation
Depression; anxiety; irritability; suspiciousness; blunted, flat or inappropriate emotion; change in appetite; reduced energy and motivation.

Changes in thinking and perception
Difficulties with concentration or attending; sense of alteration of self, others or outside world (e.g. feeling that self or others have changed or are acting differently in some way); odd ideas; unusual perceptual experiences (e.g. a reduction or greater intensity of smell, sound or colour).

Changes in behaviour
Sleep disturbance; social isolation or withdrawal; reduced ability to carry out work or social roles.

Although these signs and symptoms may not be very dramatic on their own, when they are considered together, they may suggest that something is not quite right. It is important not to ignore or dismiss such warning signs and symptoms, even if they appear gradually and are unclear. It should not be assumed that the person is just going through a phase or misusing alcohol or other drugs, or that the symptoms will go away on their own.

The signs and symptoms of psychosis may vary from person to person and can change over time. It is also important to consider the spiritual and cultural context of the person's behaviours, as what is interpreted as a symptom of psychosis in one culture may be considered to be normal in another culture. In some Aboriginal communities, for instance, being visited by spirits or hearing voices of deceased loved ones are normal experiences.[79]

People experiencing early stages of psychosis often go undiagnosed for a year or more before receiving treatment. A major reason for this is that psychosis often begins in late adolescence or early adulthood and the early signs and symptoms involve behaviours and emotions that are common in this age group.

A diagnosis of a psychotic disorder in those with a severe intellectual disability or severe communication difficulties is difficult and rarely made, as diagnosis relies largely on the person being able to explain their internal experiences.[22]

Many young people will have some of these symptoms without developing a psychosis. Others showing these symptoms will eventually be diagnosed as having one of the following disorders.

Types of psychotic disorders

Schizophrenia

The disorder in which psychosis is most commonly a feature is schizophrenia. Contrary to common belief, schizophrenia does not mean "split personality". The term schizophrenia comes from the Greek for "fractured mind" and refers to changes in mental function where thoughts and perceptions become disordered.

The major symptoms of schizophrenia include:

- ***Delusions***. These are false beliefs, for example of persecution, guilt, having a special mission or being under outside control. Although the delusions may seem bizarre to others, they are very real to the person experiencing them.

The nature of delusions and the way they are expressed by a person with an intellectual disability are similar to that in the general population. However the content of the delusions tends to less bizarre. The person with an intellectual disability is more likely to express delusions through their behaviour. Delusions may present in a person with intellectual disability as:

- new avoidance or 'fears'
- irrational beliefs not expressed before
- bizarre accusations of others
- glaring with intense anger at strangers or previously liked others
- sudden medication refusal.[2]

Control by external forces is a common delusion. Caution is needed when these statements are encountered in the person with an intellectual disability, because they generally have less control over their everyday lives than most and it may be a reality that others are controlling them.[14]

- ***Hallucinations.*** These are false perceptions. Hallucinations most commonly involve hearing voices, but can also involve seeing, feeling, tasting or smelling things. These are perceived as very real by the person, but are not actually there. The hallucinations can be very frightening, especially voices saying negative comments about the person. The person may hear more than one voice or experience many types of hallucinations. Because their delusions and hallucinations are so real to them, it is common for people with schizophrenia to be unaware they are ill.

People with intellectual disability are likely to experience and express hallucinations in ways that are consistent with their communication and developmental ability. The kind of hallucinations they experience may also be a function of their limited life experiences and interests, so they may be expressed in broader or more simplistic terms.[22] When asking a person with an intellectual disability about their auditory hallucinations it may be wise to do so on a number of occasions to check for consistency in their presentation.[14]

As with delusions, the person with an intellectual disability is more likely to demonstrate an hallucination through behaviour. Some of the common behaviours suggesting an hallucination include:

- talking to non-existent people
- turning their head or nodding as if listening to someone no one else hears
- reporting conversations not heard by others
- sniffing the air, as if smelling something not smelt by others
- pushing or brushing unseen objects off their body
- scratching
- covering their eyes or ears as if to block out hallucinations
- 'shadow boxing'

It is important in relation to both delusions and hallucinations to remember that the presentation of these may actually represent some other condition or actual reality for the person with an intellectual disability rather than a symptom of psychosis. For example:

- Because of their limited cognitive ability and social understanding, they may believe that a carer is trying to hurt them if they don't get on with that staff member or another staff member decreases their level of support to the person.
- A person may also report that others are staring at them, which they may well be due to their 'different' appearance.
- 'Fantasy thinking' may be due to other conditions such as autism and not a psychotic symptom.
- It is not uncommon to see a person with an intellectual disability talking to themselves or carrying on a conversation with an imaginary person or an inanimate object. Self-talk may be the person's way of coping with stress or of processing information. They may have 'imaginary friends' with whom they talk when lonely, bored or frightened.
- A person with an intellectual disability may have trouble recognising their own thoughts and may attribute them to others.[14]
- Hallucinations can occur in some medical conditions, for instance when a person has a high fever.

- ***Thinking difficulties.*** There may be difficulties in concentration, memory and ability to plan. These make it more difficult for the person to reason, communicate and complete daily tasks.

- ***Loss of drive.*** The person lacks motivation even for self-care. It is not laziness.

- ***Blunted emotions.*** The person does not react to the things around them or reacts inappropriately. Examples include speaking in a monotone voice, lack of facial expressions or gestures, lack of eye contact or reacting with anger or laughter when these are not appropriate.

- ***Social withdrawal***. The person may withdraw from contact with other people, even family and close friends. There may be a number of factors that lead to this withdrawal such as loss of drive, delusions that cause fear of interacting, difficulty concentrating on conversations and loss of social skills.

Additional symptoms of schizophrenia in a person with intellectual disability might include;

- deterioration of language skills or decrease in the use of language
- speech no longer present or making sense.
- sudden appearance of new unusual mannerisms
- not moving from one position for a long period of time.
- general skill deterioration
- lack of expression or emotions
- previous reinforcers (rewards) become no longer effective
- aggressive behaviour. It has been reported that most individuals with intellectual disability and schizophrenia will present with some aggressive behaviour. This may be in direct response to distressing thoughts and feelings.[37]

The important thing to look for in people with an intellectual disability is a change in the person's behaviour or level of functioning. Symptoms that are due to the person's intellectual disability will tend to be constant and long standing.[14]

Approximately 0.4% of the population have been diagnosed with schizophrenia.[80] Three quarters of people experiencing their first episode of schizophrenia have it beginning between 15 and 30 years of age.[81] It affects males more than females and males tend to develop it earlier.[82] The onset of the illness may be rapid, with symptoms developing over several week, or it may be slow and develop over months or years. Approximately one third of people who develop schizophrenia have only one episode and fully recover, another third have multiple episodes but feel well in between episodes, and a third have a life-long illness.[83]

The prevalence of schizophrenia in intellectual disability is reported to be around 3%, which is about three times higher than in the general population. The reason for this is not clear, however a partial explanation for this may be due to genetic risk factors and increased rates of obstetric complications.[14]

Bipolar disorder[84]

People with bipolar disorders have extreme mood swings. They can experience periods of depression, periods of mania and long periods of normal mood in between. The time between these different episodes can vary greatly from person to person, but usually episodes last days or weeks, distinguishing bipolar disorder from moodiness which may cause mood switches that occur on a daily basis or several times a day .It is not unusual for people with this disorder to become psychotic during depressive or manic episodes.[43, 44]

The **depression** experienced by a person with bipolar disorder has some or all of the symptoms of depression listed previously in Section 2.1 *Depression*

The difference between mania and depression for people with an intellectual disability is not as distinct as it is for the general population. People with an intellectual disability are more likely to experience rapid cycling (more than four episodes of either mania or depression in a year) than the general population.[10] Furthermore, the interpersonal problems experienced as part of bipolar disorder are less pronounced in the intellectually disabled population than in the general population.[37]

The following are common symptoms of **mania** as they may present in a person with intellectual disability. The person may have some or all of them.

- ***Increased energy and over-activity***
  - pacing, rarely sitting
  - fidgeting
  - working on many activities at once
  - increase in rituals or compulsions
  - skipping from activity to activity, leaving tasks uncompleted
  - inability to sit through previously pleasurable activities

- ***Elevated mood***

The person will feel high, happy, full of energy, on top of the world, invincible.

  - smiling, hugging or being affectionate with people who previously weren't favoured, enthusiastic greeting of everyone
  - getting into other people's space
  - hitting out at a previously favoured person
  - boisterous, playfulness and constant excitement, extreme excitement

- over-reactivity to small incidents, e.g. excessive or inappropriate laughing and giggling
- self injurious behaviour (SIB) associated with irritability
- nasty teasing
- difficult to redirect[12,37]

- ***Need less sleep than usual***. The person can go for days with very little sleep.

  - behavioural challenges when prompted to go to bed
  - constantly getting up at night
  - seeming rested after not sleeping
  - working on activities in their room during the night
  - ready for work extremely early

- ***Irritability.*** This may occur if others disagree with a manic person's unrealistic plans or ideas. Some of the literature suggests that in the intellectually disabled people irritability is more predominant than elation or elevated mood. This is likely to lead to higher levels of aggression being associated with bipolar disorder in this group. In a person with an intellectual disability, presentation may include:

  - aggressive behaviours (both physical and verbal), particularly in response to minor things that he or she wouldn't normally react to
  - self-injurious behaviour (SIB)
  - pacing
  - refusals to co-operate
  - destructive behaviour.

- ***Rapid thinking and speech.*** The person may talk too much, too fast and keep changing topics.

  - increase in singing, swearing, vocalisations
  - continually repetitive or disorganised speech
  - screaming
  - constant interrupting
  - increase in non-verbal communication
  - decrease in ability to listen
  - disconnected thoughts
  - quickly changing subjects
  - reporting that ideas are moving too fast.

- ***Lack of inhibitions.*** The person may disregard risks, spend money extravagantly or be very sexually active.

  - increased masturbation
  - sexualising previously platonic relationships
  - teasing others
  - fondling others
  - increase in intrusive behaviours like touching, hugging, clinging
  - stripping
  - giving away/spending money.

- ***Grandiose delusions.*** These involve very inflated self-esteem such as a belief that the person is superhuman, especially talented or an important religious figure. In a person with an intellectual disability these delusions are usually simpler, for example:

  - making improbable claims. Care is needed to make a distinction between "wishful thinking" and grandiose ideas. People with intellectual disability sometimes maintain that they are a staff member or possess skills they do not have. Such thinking is more likely to be grandiose if the person becomes highly distressed when their claims are challenged.
  - wearing excessive make-up
  - dressing provocatively
  - demanding rewards
  - inappropriate remarks.

- ***Lack of insight***

The person is so convinced that their manic delusions are real that they do not realise they are ill.

- **Other signs**

Additional signs that may present in a person with intellectual disability and bipolar disorder include:

  - sudden or gradual changes in usual behaviour
  - seeking reassurance
  - loss of skills
  - loss of bowel or bladder control
  - loss of ability to communicate
  - physical illness.[85]

It is important to remember that many of the symptoms associated with a manic episode are often typical features of intellectual disability, e.g. poor judgement, distractibility, excessive activity, aggression, etc. The key to determining whether a person is having a manic episode is to compare their current functioning with previous functioning. Before assuming that the person with an intellectual disability is experiencing mental health problems, look for other factors which may account for the presence of some of the signs or symptoms, e.g. hormonal changes in women, medical conditions such as epilepsy, hypoglycaemia, hyperthyroidism, substances such as caffeine, medication side effects and various environmental and seasonal factors.[12,14]

It can take people with bipolar a long time to be diagnosed correctly because the person must have had episodes of both depression and mania. It affects 1.8% of Australians aged 16 or over in any one year.[3] Males and females are equally affected. See Section 2.1 *depression* for other information about bipolar disorder.

Several studies have reported higher rates of bipolar disorder among people with intellectual disability than in the general population. Prevalence rates range from 0.9%-4.8%.[37]

Psychotic depression

Sometimes depression can be so intense it causes psychotic symptoms. For example, the person may have delusions involving feeling very guilty about something that is not their fault, believing that they are severely physical ill or that they are being persecuted or observed. Some people may also experience hallucinations, most commonly hearing voices.

Schizoaffective disorder

Sometimes it is difficult to tell the difference between schizophrenia and bipolar disorder as the person has symptoms of both illnesses. A person with schizoaffective disorder has symptoms of psychosis and depression but does not met the criteria for bipolar disorder.

Drug induced psychosis

This is a psychosis brought on by intoxication with drugs or withdrawal from drugs or alcohol. The symptoms usually appear quickly and last a short time (from a few hours to days) until the effects of the drug wears off. The most common symptoms are visual hallucinations, disorientation and memory problems. Both legal and illegal drugs can contribute to a psychotic episode, including, cannabis, alcohol, cocaine, amphetamines (speed), hallucinogens, inhalants, opioids, sedatives, hypnotics and anxiolytics.[2]

Risk factors for psychotic disorders

It is believed that psychosis is caused by a combination of factors including genetics, biochemistry and stress. Biological factors could be genetic vulnerability, changes in the brain or a dysfunction in the neurotransmitters in the brain. Stress or drug use may trigger psychotic symptoms in vulnerable people.

Risk factors for schizophrenia[86]

The following are the most significant risk factors:

- ***Having a close relative with schizophrenia***. For someone with a parent or sibling with schizophrenia, the risk is around 10-15%. Although the risk is higher, it is important to note that 85-90% will not develop schizophrenia.
- ***Male gender***. Males are more likely to develop schizophrenia and tend to have an earlier age of onset.
- ***Urban living***. People who are born and grow up in urban areas are at a higher risk than people from rural area. The reason is unknown, but could be related to differences in the health of mothers during pregnancy, cannabis use, or social stressors.
- ***Migration***. People who are immigrants of the children of immigrants, have increased risk. The reason is unknown, but social stress from feeling like an outsider could be a factor.
- ***Social stress***. Social stressors can trigger the onset of a psychotic episode. There are great differences amongst us all in how well we cope with life events. People with intellectual disability have reduced coping skills and therefore are likely to have difficulty managing events that would not trouble others. For a person with an intellectual disability, increased stress could be due to a favourite carer leaving or new carer starting, changes or loss of day placement, work or accommodation, or a new house mate or a house mate with challenging behaviour.
- ***Cannabis use***. Cannabis use during adolescence increases risk, particularly in people who have other risk factors.[87]

The following risk factors are far less significant, increasing risk by only a very small amount:

- ***Events during the mother's pregnancy.*** Infections in the mother in the first and second trimesters of pregnancy have been linked with higher incidence. A possible explanation is that the m other's immune response interferes with the brain development of the foetus. Severe nutritional deficiency and very stressful life events during pregnancy might also increase risk.
- ***Birth complications.*** A range of complications are associated with approximately double the risk, perhaps because of lack of oxygen (hypoxia) to the infant's brain.
- ***Winter/spring birth.*** Birth during the late winter or early spring is associated with 5-10% greater risk. The explanation is not known, but may be related to infection, malnutrition or genetic mutation.
- ***Older age of father.*** Older age at the time of conception roughly doubles the risk. The explanation is not known, but may be related to impaired sperm and genetic mutation.

While there are a large number of possible risk factors for schizophrenia, these lead to biochemical changes in the brain. One of the major known changes is to the neurotransmitter dopamine.[88] Antipsychotic medications that are used for schizophrenia work by altering dopamine levels in the brain.

Risk factors for bipolar disorder[89]

The causes of this disorder are not fully understood. However, the following facto is known to be involved:

- ***Having a close relative with bipolar disorder.*** This is the most important risk factor known. Someone with a parent or sibling affected has around 9% risk.[90] While this is an increased risk, it means that over 90% of people with an affected relative will not develop the disorder.

No other risk factors are firmly established. However, there is some research supporting the following.

- ***Pregnancy and obstetric complications.*** These complications may affect the developing brain of the foetus or infant.
- ***Birth in winter or spring.*** This may reflect risk to the foetus from infections or other events that vary by season.
- ***Social situation.*** People who develop bipolar disorder are more likely to have lower income, be unemployed, single and live in urban areas. However, these factors may be consequences of the very early changes produced by bipolar disorder, rather than the causes.
- ***Recent stressful life events.*** Stressful events are more common in the 6 months before onset of an episode. For a person with intellectual disability increased stress could be due to a favourite carer leaving, changes or loss of day placement, work or accommodation, a new house mate or a house mate with challenging behaviour.
- ***Recent childbirth.*** Women appear to be at increase risk in the months following childbirth.
- ***Brain injuries.*** Brain injury before age 10 years may increase risk.
- ***Multiple sclerosis.*** People with multiple sclerosis may have increased risk.

Similar to schizophrenia, the various risk factors for bipolar disorder can lead to biochemical changes in the brain that produce mania and depression.

Interventions for psychotic disorders

Professionals who can help

A variety of health professionals can provide help to a person with psychosis. They are:

- GPs
- Mental health professionals
- Psychiatrists
- Psychologists
- Counsellors
- Mental health nurses
- Case managers.
- More information about how these professionals can help is available in Section 1.1 *Mental Health Problems and Intellectual Disability in Australia*.

Treatments available for psychosis

There are two aspects to professional help for psychosis that need to be considered. The first is medication and the second is treatment to improve outcomes and maximise quality of life.
Medication is essential to the management of a psychotic illness different psychotic illnesses required different medications and are described below. It is not realistic to expect o manage a psychotic illness without medication. A person with a psychotic illness will need to work closely with their doctors to determine the best medications to effectively manage the illness with a minimum of side effects. A person who is experiencing severe psychosis may benefit from a short stay in the hospital to get back on track.

Psychiatrists, psychologist, counsellors and other mental health professionals may be able to help improve quality of life by helping the person to learn to accept their illness, facilitate good employment or education opportunities and help to maintain good family and social relationships. They may also be able to provide psychoeducation to the person and their family and/or carers to promote good understanding and illness management strategies.

The pattern of recovery from psychosis varies form person to person. Some people recover quickly with intervention while others may require support over a longer period. Recovery from the first episode usually take a number of months. If symptoms remain or return, the recovery process may be prolonged. Some people experience a difficult period lasting months or even years before effective management of further episodes of psychosis is achieved. Most people recover form psychosis and lead satisfying and productive lives.

There are a range of treatments that have good evidence in the treatment of psychosis.

Schizophrenia treatments[91]

In the past, people with schizophrenia were considered to have a chronic illness with no hope of recovery. It is now known that people who get

proper treatment can lead productive and fulfilling lives. In fact, research has demonstrated that recovery is possible for many people who are treated with medications and psychosocial rehabilitation programs. People with schizophrenia and other psychotic disorders need to be treated with optimism for a good outcome and in a spirit of partnership. They need to live in a stable and secure social environment. This includes a pleasant home environment, support from family and friends, an adequate income and a meaningful role in society.[92] There is evidence that the following specific treatment help people with schizophrenia.

- ***Antipsychotic medications.*** These are effective for psychotic symptoms such as hallucinations. However, they are less effective for other symptoms such as lack of motivation, poor memory and problems with concentration.
- ***Antidepressant medications.*** People with schizophrenia may have depression symptoms as well. Antidepressants are effective fore treating these symptoms. ***Physical health checks.*** People with schizophrenia often suffer from poor physical health and may die prematurely as a result of preventable or treatable illnesses. It is important to have ongoing physical health checkups with a GP.
- ***Psychoeducation*** means education and empowerment of the person and their family and carers about their illness and how best to manage it. This helps to reduce relapses. Family tension, a common result of trying to deal with a poorly understood disability, may contribute to a relapse in the person with schizophrenia, and psychoeducation can help to avoid this.
- ***Cognitive behaviour therapy.*** This type of psychological therapy can help reduce psychotic symptoms by helping the person to develop alternative explanations of schizophrenia symptoms, reducing the impact of the symptoms on their life, and encouraging the person to take their medication. ***Social skills training*** is used to improve social and independent living skills.
- ***Assertive community treatment*** is an approach for people experiencing more severe illness. The care of the person is managed by a team of various kinds of health professionals, such as psychiatrist, nurse, psychologist and social worker. Care is available 24 hours a day and is tailored to the person's individual needs. Support is provided to family members and carers as well. Assertive community treatment has been found to reduce relapses and the need for hospitalisation.

Bipolar disorder treatments[93]

There is evidence that the following treatments help people with bipolar disorder:

- ***Medications.*** There are a range of medications that can help people with bipolar disorder. These include mood stabilisers, antipsychotics and antidepressants.
- ***Psychoeducation*** involves providing information the person about bipolar disorder, its treatment and managing its effect on their life. Psychoeducation has been found to reduce relapses when used together with medication.
- ***Psychological therapies.*** Two therapies that research has found to be helpful are *cognitive behaviour therapy* and *interpersonal and social rhythm therapy.* Cognitive behaviour therapy helps people to monitor mood swings, overcome thinking patterns that affect mood, and to function better. Interpersonal and social rhythm therapy cover potential problem areas in the person's life (grief, changes in roles, disputes, and interpersonal deficits), and helps them regulate social and sleep rhythms.
- ***Family therapy*** educated family members on how they can support he person with bipolar disorder and avoid negative interactions that can trigger relapses.

Additional treatment considerations for a person with intellectual disability and psychosis.

- Medications should be used where possible in combination with other interventions that provide the person with skills to manage their mental illness. Medications should be frequently reviewed by a GP or psychiatrist.
- The degree to which the type of CBT needs to be adapted and the efficacy of it will depend on the person's level of disability, the problem it is being used to address and the professional's understanding of intellectual disability.
- Education of support staff /carers regarding Bipolar Disorder, is also an important aspect of supporting a person with intellectual disability and bipolar disorder.
- **Environmental/social modifications** may be required to (e.g. increased supervision) in order to ensure the person with an intellectual disability's safety.

Importance of early intervention for psychosis

Early intervention for people with psychosis is most important. Research has shown that the longer the delay between the onset of psychosis and the start of treatment, the less likely the person is to recover.[7] Other consequences of delayed treatment include:[78]

- Poorer long term functioning
- Increased risk of depression and suicide
- Slower psychological maturation and slower uptake of adult responsibilities
- Strain on relationships with friends and family and subsequent loss of social supports
- Disruption of study and employment
- Increased use of drugs and alcohol
- Loss of self-esteem and confidence
- Greater chance of problems with the law

Crises associated with psychosis

Crises that may be associated with psychosis are:

- The person is in a **severe psychotic state**
- The person is showing **aggressive behaviour**
- The person has **suicidal thoughts and behaviours**

Severe psychotic states

People with psychotic disorders can have periods where they become very unwell. They can have overwhelming delusions and hallucinations, very disorganised thinking and bizarre and disruptive behaviours. The person will appear very distressed or their behaviours will be disturbing to others. When a person is in this state, they can come to harm unintentionally because of their delusional beliefs or hallucinations, e.g. The person believes they have special powers to protect them from danger such as driving through red lights, or the person may run through traffic to try to escape from their terrifying hallucinations.

Aggressive behaviours

A very small percentage of people experiencing psychosis may threaten violence.[94] People with mental illnesses are often portrayed in the media as possibly unpredictable, violent or dangerous. However, the vast majority of people with mental illnesses are not dangerous to others. Only a small proportion (up to 10%) of violence in society is carried out by people with mental illness.[95,96] depression and anxiety disorders have little or no association with violent behaviour towards others. However, there is an increased risk of violence for people who experience substance use disorders, personality disorders or psychosis.[97] The use of alcohol or other drugs has a stronger association with violence than do mental illnesses. Many crimes are committed by people who are intoxicated with alcohol or other drugs. The risk of violence is greater when the person with psychosis is not being adequately treated or is using alcohol or other drugs.

Suicidal thoughts and behaviours

Psychotic disorders involve a high risk of suicide. Approximately 5% of people with schizophrenia complete suicide.[98] About 10-20% of individuals with bipolar disorder take their own life.[99] having concurrent depression or a substance use disorder increases this risk.[74]

The main factors to be taken into account when assessing risk of suicide in people experiencing psychotic symptoms are:[99, 100]

- Depression
- Suicidal thoughts, threats or behaviour
- Previous suicide attempt
- Poor adherence to treatment
- Fears of the impact of the illness on mental functioning
- Drug misuse.

Suicidal thinking and high risk taking behaviour in those with an intellectual disability should always be investigated. The method chosen by a person with an intellectual disability may not have any lethal potential but may have been chosen because the person believed it would be fatal, so the intent is still there.[12]

Mental Health First Aid Action Plan for People with an Intellectual Disability and Psychosis[101, 102]

1. **Approach the person , assess and assist with any crisis**
2. **Listen non-judgementally**
3. **Give support and information**
4. **Encourage and support the person to get appropriate professional help.**
   The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered
5. **Encourage other supports.**
   The person with an intellectual disability may need assistance to do this

ACTION 1:
Approach the person, assess and assist with any crisis

How to approach

People developing a psychotic disorder will often not reach out for help. Someone who is experiencing profound and frightening changes such as psychotic symptoms will often try to keep them a secret. If you are concerned about someone, approach the person in a caring and non-judgemental manner to discuss your concerns. Let the person know that you are concerned about them and want to help. The person you are typing to help might not trust you or might be afraid of being perceived as 'different', and therefore may not be open with you. If possible, you should approach the person privately about their experiences in a place that is free of distractions. Try to tailor your approach and interaction to the way the person is behaving.. e.g. if the person is suspicious and avoiding eye contact, be sensitive to this and give them the space they need. Do not touch the person without their permission. If the person is unwilling to talk with you, do not try to force them to talk about their experiences. Rather, let them know that you will be available if they would like to talk in the future. You should state the specific behaviours you are concerned about and should not speculate about the person's diagnosis. It is important to allow the person to talk about their experiences and beliefs if they want to. As far as possible, let the person set the pace and style of the interaction. You should recognise that they may be frightened by their thoughts and feelings.

When asking questions of a person with an intellectual disability it is important to:

- Communicate in a way that will assist them to understand e.g. by using visual aids,
- Check they have understood what you are asking by getting them to tell you in their own words, pictures, signs what they think you are asking them.
- Avoid asking leading questions.
- Be aware that people with an intellectual disability will often answer in the affirmative in order to please or appear capable so check that what they say is what they really mean.

As you talk with the person, be on the lookout for any indications that the person may be in crisis.

*If you have concerns that the person **is in a severe psychotic state,*** find out how to **assess** and **assist** this person in *Section 3.5 First Aid for Severe Psychotic States.*

*If you have concerns that the person **is showing aggressive behaviour,** find out how to **assess** and **assist** this person in Section 3.8 First Aid for Aggressive Behaviours.*

*If you have concerns that the person may be having **suicidal thoughts and behaviours,** find out how to **assess** and **assist** in Section 3.1 First Aid for Suicidal Thoughts and Behaviours.*

If you have no concerns that the person is in crisis, you can ask them about how they are feeling and how long they have been feeling that way and move on to ACTION 2.

ACTION 2:
Listen non-judgementally

The person may be behaving and talking differently due to psychotic symptoms. They may also find it difficult to tell what is real from what is not.

What you should try to do:

- Understand the symptoms for what they are
- Empathise with how the person feels about their beliefs and experiences.

What you should try not to do:

- Confront the person
- Criticise or blame them
- Take their delusional comments personally
- Use sarcasm
- Use patronising statements
- State any judgements about the content of those beliefs and experiences.

When listening to a person with an intellectual disability, you may need to use more checking questions and paraphrasing to ensure that you have understood correctly. It is far better to ask the person to repeat what they said, or to say it in a different way, than to pretend that you have understood them or to assume that they have understood you.

See Action 2 in Section 2.1 *Depression* for more tips on non-judgemental listening.

Dealing with delusions and hallucinations

It is important to recognise that the delusions and hallucinations are very real to the person. You should not:

- Dismiss, minimise or argue with the person about their delusions or hallucinations. Remember the persons experiences are very real to them, however unbelievable they may seem to others[22]
- Act alarmed, horrified or embarrassed by the person's delusions or hallucinations
- Laugh at the person's symptoms of psychosis
- Encourage or inflame the person's paranoia, if the person exhibits paranoid behaviour.

You can respond to the person's delusions without agreeing with them by saying something like "That must be horrible for you" or "I can see you are upset". If the person has some coping strategies, such as using a music player or mobile phone when they are hearing voices, encourage them to use these. You could also try getting them to think about something else by talking about an unrelated topic of interest to them, or by changing the activity you are doing with them.[22]

Dealing with communication difficulties

People experiencing symptoms of psychosis are often unable to think or communicate clearly. Ways to deal with communication difficulties include:

- Responding to disorganised speech by communicating in an uncomplicated and succinct manner
- Repeating things if necessary
- Being patient and allow plenty of time for the person to process the information and respond to what you have said.
- Being aware that it does not mean that the person is not feeling anything, even if the person is showing a limited range of feelings
- Not assuming the person cannot understand what you are saying even If their response is limited.

Responding to a person with intellectual disability who is showing signs of mania

- Reduce stimulation e.g. radios, TV's
- Reduce consumption of stimulants (tea, coffee, chocolate)
- Don't get caught up in the person's euphoria or unrealistic expectations
- Don't try to argue or convince the person that his/her plans are unrealistic
- Keep conversations brief and to the point since a person with mania has a very short attention span.
- Try not to be authoritative. But be firm, practical and realistic. Don't try to force the person to do something as this will likely result in aggression or SIB.
- Limit their ability to spend money
- Encourage sleeping via a soothing environment (e.g. soft music, low lighting, and minimal stimulation) and other techniques which may cue sleep such as reading stories, a glass of milk, engaging in a bedtime routine.[37]

ACTION 3:
Give support and information

Treat the person with respect and dignity

It is important to respect the person's autonomy while considering the extent to which they are able to make decisions for themselves. Equally, you should respect the person's privacy and confidentiality unless you are concerned that the person is at risk of harming themselves or others. It is important that you are honest when interacting with the person.

Offer consistent emotional support and understanding

Reassure the person that you are there to help and support them, and that you want to keep them safe. Try to reduce any unnecessary stresses.

Provide practical help

Try to find out what type of assistance they need by asking what will help them to feel safe and in control. If possible, offer the person choices of how you can help them so that they are in control. Do not make any promises that you cannot keep. This can create an atmosphere of distrust and add to the person's distress.

You could also;

- Help ground the person in reality by discussing for example, what they are doing, what they ate at lunch, the weather and anything else which refers the person back to reality.
- Maintain normal routines as much as possible.
- Help the person to stay away from unhelpful substances such as alcohol, caffeine and other unprescribed drugs.

Offer information

When a person is in a severe psychotic state, it is usually difficult and inappropriate to give information about psychosis. When the person is more lucid and in touch with reality, you could ask the person if they would like some information about psychosis. If they do want some information, it is important they you give them resources that are accurate and appropriate to their situation.

For people with an intellectual disability information and reassurance needs to be given in a way that will promote understanding, e.g. keep sentences short and simple, and don't use jargon; write or draw ideas on paper for them. Check their understanding by asking them to tell you in your own words or way what you have just told them.

Information and education on psychosis should be made available to staff and carers so they can provide appropriate and ongoing support.

ACTION 4:
Encourage and support the person to get appropriate professional help

Discuss options for seeking professional help

You could 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 decided to seek professional help, you should make sure that they are supported both emotionally and practically in accessing services. If the person does seek help, and either they or you lack confidence in the medical advice they have received, they should seek a second opinion from another medical or mental health professional.

The person with an intellectual disability may need additional support to link them with appropriate professional help. These professionals will require good information about the person with an intellectual disability so it is important to involve a support person who knows the person well.

You may need to stay with them longer, or if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access a professional. Pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.[21]

It is important to take with you to a professional's appointment any information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

What if the person doesn't want help?

The person may refuse to seek help even if they realise they are unwell. Their confusion and fear about what is happening to hem may lead them to deny that anything is wrong. In this case you should encourage them to talk to someone they trust. It is also possible that a person may refuse to seek help because they lack insight that they are unwell. They might actively resist your attempts to encourage them to seek help. In either case, your course of action should depend on the type and severity of the person's symptoms.

It is important to recognise that unless a person with psychosis meets the criteria for involuntary committal procedures, they cannot be forced into treatment. If they are not at risk of harming themselves or others, you should remain patient, as people experiencing psychosis often need time to develop insight regarding their illness. Never threaten the person with mental health legislation or hospitalisation. Instead remain friendly and open to the possibility that they may want your help in the future.

ACTION 5:
Encourage other supports
Other people who can help

Try to determine whether the person has a supportive social network and, if they do, encourage and support them to use these supports.

Family and friends are an important source of support for a person experiencing a psychotic illness. A person is less likely to relapse if they have good relationships with family.[103] Family, friends and support workers can help by:

- Listening to the person without judging or being critical. Be empathic to their concerns and provide comfort where possible.
- Keeping the person's life as stress-free as possible to reduce the chance of a relapse
- Encouraging and providing support to the person to get appropriate treatment and support
- Checking if the person is feeling suicidal and taking immediate action if the person is suicidal
- Providing the same support as they would for a physically ill person- these include sending get-well cards, flowers, phoning or visiting the person, and helping out if they cannot manage.
- Having an understanding of psychosis
- Looking for support from a carers' support group
- Helping the person to develop an advance directive, wellness plan, relapse prevention plan and/or personal directive.

What is an advance directive?
An advance directive is a document describing how the person wants to be treated when they are unable to make their own decisions due to their present state of illness. In an advance directive, the person appoints someone they trust to assist with the decision-making at that time.

In looking to family and friends of the person with an intellectual disability for support, it is important to keep in mind that they may be under stress or 'burnt out' due to their burden of care.

Support groups can be helpful to the person experiencing psychosis and other family members and carers.

Self-help strategies

People experiencing psychosis should avoid the use of alcohol, cannabis and other frugs. People sometimes take drugs as a way of coping with a developing psychotic illness. But these drugs can make the symptoms worse, initiate relapse and make the disorder difficult to diagnose.[104] The use of cannabis can also slow down recover..[105]

Many people experiencing psychosis also have depression or anxiety. Many of the self-help strategies recommended for depression and anxiety are also appropriate for people with psychosis. However, they should not be used as the main form of assistance. Mental health professionals must be consulted.

The person with an intellectual disability may have few if any self-help strategies due to their reduced cognitive abilities, lack of experience and education. Disability specific services may offer specialised education programs to assist people to learn self-help strategies and generalise them into their everyday life. It is useful to contact the state government disability service in your locality for information about what is available. If the person with an intellectual disability does have some strategies, they may need a reminder as to what they are, and then additional support to put these into practice.

Not all self-help strategies are suitable for all people with psychotic illnesses; for example, SAMe may trigger mania in people with bipolar disorder.[106] The benefits of exercise for depression have been well studied but little research has been done on exercise in bipolar disorder. People with bipolar disorder may benefit from an exercise regime, but should be wary when there are warning signs of a manic episode. If exercise appears too stimulating during those times, decreasing the frequency or intensity of exercise until the warning signs or episode have passed may be a good idea.

HELPFUL RESOURCES
for psychosis

Websites

Black Dog Institute
www.blackdoginstitute.org.au

The Black Dog Institute is an organisation based in Sydney which provides clinical services, education and research on bipolar disorder. The website gives information about this disorder, including a self-assessment test, downloadable fact sheets and a spoken education program.

Early Psychosis Prevention and Intervention Centre
http://www.eppic.org.au

EPPIC is a mental health service in Western Melbourne aiming to meet the needs of adolescents and young adults with emerging psychotic disorders. This website has excellent downloadable information sheets on psychosis. These are available in many languages besides English

National Institute of Mental Health
www.nimh.nih.gov

This US government website gives a wealth of excellent up-to-date information on psychosis in the form of downloadable booklets and fact sheets.

SANE Australia
http://www.sane.org/

SANE Australia is a national charity working for a better life for people affected by mental illness. Its website has information and podcasts on a range of mental illnesses, including psychotic disorders. SANE also runs a helpline providing information (see below).

Books
Schizophrenia

Compton MT, Broussard B. (2009). *The first episode of psychosis: A guide for patient and their families.* Oxford University Press, Oxford, England.
This US guide is for people who have had a first psychotic episode and their families. It encourages them to take an active informed role in their care.

Jones S, Hayward P. (2204). *Coping with schizophrenia: a guide for patients, families and caregivers.* Oneworld Publications, Oxford, UK.
This guide designed for people with a diagnosis of schizophrenia, their caregivers, friends and families addresses myths and includes personal stories from people who are recovering.

De Hert M, Magiels G, Thys E. (2003). *The secret of the brain chip. A self-help guide for people experiencing psychosis.* EPO, Antwerp, Belgium.
This self-help guide incorporates a graphic novel with information about psychosis, its treatment and how to stay well. Its contents can be accessed free at the following website: www.psychiatry24x7.com. Follow the link to 'Bipolar disorder' and click on the 'Self-help guide' link. Once a person ahs registered to receive the content, it is delivered a chapter at a time via email over several weeks.

Deveson, A. (1998). *Tell me I'm here.* Penguin, Ringwood Vic, Australia
This memoir tells of an Australian family's experience of a son with schizophrenia. Anne Deveson, the young man's mother, is an Australian journalist who tells the story with great skill and insight.

Bipolar disorders

Bauer MS, Kilbourne AM, Greenwald DE, Ludman E (2009). *Overcoming bipolar disorder.* New Harbinger Publications, Oakland, CA, USA
A self-help guide for people who are in treatment for bipolar disorder and includes strategies for preventing relapse, safe and effective goal setting and medication.

Berk L, Berk M, Castle D, lauder S. (2008). *Living with bipolar: A guide to understanding and managing the disorder.* Allen and Unwin, Crows nest, NSW, Australia.
This Australian book provides practical information for people with bipolar disorder, their families and friends.

Eyers K, Parker G (eds). (2008). *Mastering bipolar disorder: an insider's guide to managing mood swings and finding balance.* Allen and Unwin, Sydney, NSW, Australia.
This book, produces by the Black Dog Institute, incorporates the latest research on bipolar disorder and personal stories of people with bipolar disorder.

Help Lines

SANE helpline
Information and advice is available by calling the SANE Helpline, 1800 18 SANE (7263), 9-5 weekdays EST.

Mental Health Crisis Numbers

ACT:
Mental Health Triage Service, 24hrs, 7 days
1800 629 354 or 02 6205 1065

NSW:
Ring nearest hospital

NT:
Darwin Top End Mental Health Services
08 8999 4988

QLD:
Call Emergency Services 000 or
Lifeline 13 11 14

SA:
Crisis Team 13 14 65

TAS:
03 6233 2388 or 1800 332 388
(9am – 11pm) or nearest hospital

VIC:
Ring the nearest hospital which will contact nearest crisis team

WA:
Crisis team 1800 676 822

Support Groups

Schizophrenia Fellowship and Mental Illness Fellowship
These organisations provide support for people with schizophrenia and their families in all states and territories. For contact details in your area, see the White Pages.

ARAFMI
http://www.arafmiaustralia.asn.au/
ARAFMI provides support for families, carers and friends with mental health issues. This is based on the principles of mutual self-help and support to build the capacity of families and improve their quality of life. Details of branches in various states and territories can be found at the national website above.

Support groups for people with bipolar disorder
These groups exist in many regions and go under various names. They can be contacted through local mental health services.

2.4 SUBSTANCE MISUSE

Ho Ho Ho

2.4 Substance Misuse

What is substance misuse?

Different substances affect the brain in different ways. People use substances because of these effects, which include increasing feelings of pleasure or decreasing feelings of distress. Using alcohol or drugs does not in itself mean that a person has a substance use disorder.

Substance use disorders include either of the following:[2]

- **Abuse** of alcohol or other drugs, i.e. use which leads to problems at work, school or home, or to legal problems or damage to health: and
- **Dependence** on alcohol or other drugs.
- The symptoms of substance dependence are:
- Tolerance for the substance (the person needs increased amounts over time or gets less effect with repeated use)
- Problems in withdrawal (person experiences withdrawal symptoms or uses the substance to relieve withdrawal symptoms)
- Use of larger amounts or over longer periods than intended
- Problems in cutting down or controlling use
- A lot of time is spent getting the substance, using it, or recovering from its effects
- The person gives up or reduces important social, occupational or recreational activities because of substance use
- The person continues using the substance despite knowing they have persistent physical or psychological problems from use.

Approximately 5.1% of Australians aged 16 years or over have a substance use disorder in a given year. Alcohol use disorders affect 4.3% and other drug use disorders 1.4%. Males are affected by substance use disorders more than females (7.0% vs. 3.3%).[3] Substance use disorders tend to begin in adolescence or early adulthood with a median age of onset of 18 years[15] which means that half the people who will ever have a substance use disorder will experience its onset before this age.

Substance use disorders often co-occur with mood, anxiety and psychotic disorders. People with a psychotic disorder are over four times as likely to have an alcohol use disorder and over ten times as likely to have another drug use disorder compared to people without a psychotic disorder.[5] People with an anxiety disorder or a mood disorder are three times as likely to have a substance use disorder.[39] One reason for this is that many people use alcohol or other drugs to relieve unpleasant emotions.[107] However, alcohol or other drug use can also cause other problems in a person's life (e.g. relationship or financial problems) and heavy use may contribute to or exacerbate a mental illness.

There is relatively little information about Substance Misuse in those with an intellectual disability. However it appears that between 1 and 6% of people with intellectual disability have a problem with the use of alcohol or other drugs [108-111] This is lower than the general population. Predictably, use of these substances is generally restricted to those with lesser degrees of disability.[112]

Drug and alcohol abuse are less likely in supported environments where staff are involved in the person's social life, where there is some kind of tenancy agreement involving conduct or where money is under the supervision of staff.[19] Limited income and a lack of knowledge about how to purchase drugs in particular may limit a person with intellectual disability's access to substances.

There are now a greater number of adolescents and adults with an intellectual disability living in the community. This provides opportunities for greater freedom from restriction, autonomy, income and access to the community, as well as respect for individual choices. These conditions have provided greater opportunity for substance use and misuse.[42] However, once they have started; it appears that people with intellectual disability are less likely to give up use than their non-disabled peers.[113]

Given the problems with low self esteem that are common to people with an intellectual disability, they appear to be particularly prone to reliance on alcohol and other drugs for a sense of being an equal and belonging that these offer and for the way they can compensate for poor social skills. People with an intellectual disability are also more vulnerable to stress and have reduced self regulation and coping skills. They may therefore be more likely to resort to alcohol and cigarettes as a way of coping with their mental health symptoms.

A number of associated medical and psychological difficulties common to those with a substance use disorder are likely to be magnified in people with an intellectual disability who suffer from a substance use disorder.

Alcohol

Alcohol makes people less alert and impairs concentration and coordination. Some people use alcohol to reduce anxiety and, in the short term, it can help with this. In small quantities, alcohol causes people to relax and lower their inhibitions. They can feel more confident and often act more extroverted. However, alcohol use can produce a range of short-term and long-term problems.

Short-term problems caused by alcohol intoxication[114, 115]

When a person is intoxicated, they are at risk of a number of problems, such as:

- ***Physical injuries.*** People are more likely to engage in risky behaviour which can lead to injury or death. Alcohol is a big contributor to traffic accidents. Also, intoxication can in itself lead to poor motor co-ordination resulting in staggering or falling and slurred speech, and even to medical emergencies such as continual vomiting or unconsciousness.

- ***Aggression and antisocial behaviour.*** People can become aggressive and are at a much higher risk of committing crimes.

- ***Sexual risk taking,*** e.g. not using condoms or contraceptives, and multiple sexual partners. The consequences of these behaviours can be unwanted sexual contact, unwanted pregnancy and sexually transmitted infections.

- ***Suicide and self-injury.*** When a person is intoxicated, they are more likely to act on suicidal thoughts or injure themselves. Alcohol increases risk in several ways. It acts as a mood amplifier, intensifying feelings of anxiety, depression or anger, reduces inhibitions, and inhibits the use of more effective coping strategies.

Long-term problems caused by alcohol use[114, 115]

With heavy and prolonged use, alcohol can cause physical, psychological and social problems.

- ***Alcohol use disorders.*** People who regularly drink alcohol above the recommended levels (see below), particularly those who start at an early age, have an increased risk of developing an alcohol use disorder.

- ***Other substance use disorders.*** People who use alcohol are more likely to be introduced to other drugs.

- ***Depression and anxiety.*** Heavy alcohol use increases risk of depression and anxiety. If a person is feeling suicidal, they are more likely to attempt suicide when under the effect of alcohol.

- ***Social problems.*** Abuse of alcohol is associated with family conflict, dropping out of school, unemployment, social isolation and legal problems.

- ***Physical health problems.*** In the long term, heavy use of alcohol can produce problems such as liver disease, brain damage, heart impairment, cancers, diabetes, muscle weakness, pancreatitis, ulcers and gastrointestinal bleeding, nerve damage to hands and feet, weight gain, and risks to unborn babies.

Alcohol has an adverse interaction with anti-epileptic medication. This may increase the risk of seizures and could lead to further brain damage. Given that epilepsy is more common among people with intellectual disability, they are at a greater risk of their epilepsy being worsened by alcohol misuse.[112]

How much is too much?

Many people drink alcohol and in most cases this will not lead to any damage to their health. In 2009 the National Health and Medical Research Council made the following recommendations for levels of drinking to help reduce the risk of alcohol-related harm over a person's lifetime:[114]

For health men and women aged 18 years and over:

- Drinking no more than two standard drinks on any day reduces the lifetime risk of harm.
- Drinking no more than four standard drinks on a single occasion reduce the risk of alcohol-related injury arising from that occasion.

- **For women who are pregnant, are planning a pregnancy or are breastfeeding:**

- Not drinking is the safest option

Number of standard drinks in various alcoholic beverages[114]

Alcoholic beverage	Standard Drinks
Low strength beer (2.75% alcohol)	
1 can or stubbie	0.8
285 ml glass	0.6
425 ml glass	0.9
Mid strength/light beer (3.5% alcohol)	
1 can or stubbie	1
285 ml glass	0.8
425 ml glass	1.2
Full strength beer (4.9% alcohol)	
1 can or stubbie	1.4
285 ml glass	1.1
425ml glass	1.6
Wine (9.5%-13% alcohol)	
100ml glass	1
Avge restaurant serving (150ml)	1.4-1.6
750ml bottle	7-8
Spirits (37%-40% alcohol)	
1 nip (30ml)	1
700ml bottle	22
Pre-mixed spirits (5%-7% alcohol)	
1 can (375ml)	1.5-2.1
1 bottle (275ml)	1.1-1.5

Measuring drinks

A standard drink contains about 10 grams of alcohol. The table shows the number of standard drinks in various alcoholic beverages.

It is useful to be aware of the terms used to describe drink sizes. In most parts of Australia, a 285 ml glass of beer is called a midi, a half-pint or a pot. A 425 ml glass is usually called a schooner. A pint of beer is 570 ml. however, regional differences exist. The size of a wine glass may vary from venue to venue, though many are marked to the point of a standard drink. When drinking alcohol at home, particular care should be taken as glass sizes vary and many people do not measure the amount of alcohol they put in a glass.

Other drugs

Cannabis is by far the most commonly used illicit drug in Australia.[6] However, there are a wide variety of other drugs that can lead to abuse or dependence.

Cannabis

Cannabis is a mind-altering drug and is a mixture of dried, shredded leaves, stems, seeds, and flowers of the hemp plant. The main active chemical in cannabis is THC (delta-9-tetrahydrocannabinol). The effects of cannabis on the user vary depending on how much THC it contains. The THC content of cannabis has been increasing since the 1970s. Use of cannabis can interfere with performance at work or at school and lead to increased risk of accidents if used while driving. Long-term heavy use of cannabis has been found to produce abnormalities in certain parts of the brain.[116]

The 2007 National Drug Strategy Household Survey of Australians aged 14 years or older found that 9.1% had used cannabis in the past year.[117] Although it is the most commonly used illicit drug in Australia, most users do not develop a substance use disorder, i.e. reach the stage of abuse or dependence. Only 1% of Australians aged 16 or over have a cannabis use disorder,[6] although it is more common in young people and amongst males.

Cannabis use is associated with other mental health problems. People who use cannabis are more likely to suffer from a range of other mental health problems, including anxiety and depression, but it is unclear which comes first. Also cannabis use by adolescents and young adults has been found to increase the risk of developing schizophrenia, particularly in people who are vulnerable because of a personal or family history of schizophrenia.[31] Given the reduced coping skills of people with intellectual disability, it could be possible that they may be more prone to the triggering of psychosis that cannabis can produce.

Research suggests the majority of cannabis users significantly reduce consumption during their 20s when responsibilities increase and life stability occurs. However, for people with an intellectual disability, this change may not occur to the same degree. This is due to ongoing needs for support, social difficulties and limited work opportunities. As such, it is possible that cannabis smokers with an intellectual disability may have less motivation to stop using cannabis when they reach adulthood.[113]

Opioid drugs (including heroin)

Opioid drugs include heroin, morphine, opium, and codeine. Heroin is processed from morphine, which is a naturally occurring substance taken from the Asian poppy plant. Heroin is not a widely used drug in Australia. The 2007 national Drug Strategy Household Survey found that only 0.2% of Australians aged 14 or over had used heroin in the past year.[117] However, it is a highly addictive drug, and most people who use it develop a substance use disorder. Heroin produces a short-term feeling of euphoria and well-being and relief of pain. Most people who are dependent on heroin also have associated problems such as depression, alcohol dependence and criminal behaviour. People who use heroin are at higher risk for suicide.

Pharmaceutical drugs used for non-medical purposes.

A number of prescription drugs, such as those used to tret anxiety and sleep problems, are used by some people for non-medical purposes. The 2007 national Drug Strategy Household Survey showed that 3.6% of people aged 14 or older used prescription drugs for non-medical purposed in the past year,[117] e.g. pain killers, tranquillisers or sedatives. Abuse of these drugs can lead to dangerous situations, such as driving while under the influence.

Even when used under prescription, some people will become dependent on these medications after long-term use. Older people are the most likely to be affected. When used long-term, these medications can increase the risk of falls and cognitive impairment in older people.

Cocaine

Cocaine is a highly addictive stimulant drug. Although sometimes thought of as a modern drug problem, cocaine has been abused for more than a century, and the coca leaves from which it is made have been used for thousands of years. The 2007 National Drug Strategy Household Survey showed that 1.6% of people aged 14 or older had used cocaine in the past year.[117] Cocaine gives very strong euphoric effects and people can develop dependence after using it for a very short time. With long-term use people can develop mental health problems such as paranoia, aggression, anxiety and depression. Cocaine can bring on an episode of drug-induced psychosis.

Amphetamines (including methamphetamine)

Amphetamines belong to the category of stimulant drugs and have the temporary effect of increasing energy and apparent mental alertness. However, as the effect wears off, a person may experience a range of problems including depression, irritability, agitation, increased appetite and sleepiness. Amphetamines come in many shapes and forms and are taken in different ways. They can be in the form of a powder, tablets, capsules, crystals or liquid. Methamphetamine has a chemical structure similar to that of amphetamine, but it has stronger effects on the brain. The effects of methamphetamine can last 6-8 hours. After the initial 'rush', there can be a state of agitation, which can lead to violent behaviour in some individuals. The 2007 National Drug Strategy Household Survey found that 2.3% of Australians aged 14 or over had used amphetamines over the past year.[117] High doses of amphetamines can lead to aggression, intense anxiety, paranoia, and psychotic symptoms. Withdrawal symptoms can include temporary depression. A particular mental health risk is amphetamine psychosis or "speed" psychosis, which involves symptoms similar to schizophrenia. The person may experience hallucinations, delusions and uncontrolled violent behaviour. The person will recover as the drug wears off, but is vulnerable to further episodes of drug-induced psychosis if the drug is used again.

Some types of amphetamines have legitimate medical uses. They are frequently prescribed for people with an intellectual disability. They have been found to be effective in managing disorders such as attention-deficit/hyperactivity disorder (ADHD).[118] When prescribed and administered properly, amphetamines are a valuable treatment. The dosage prescribed is much lower than is typical for recreational use and unlikely to be addictive. However those supporting people with an intellectual disability should ensure that medication is reviewed regularly and their use monitored for the possibility of inadvertent addiction.

Hallucinogens

Hallucinogens are drugs that affect a person's perceptions of reality. Some hallucinogens also produce rapid, intense emotional changes. The 2007 National Drug Strategy Household Survey frond that 0.6% of people aged 14 or older used hallucinogens in the past year.[117] In Australia the most widely used hallucinogenic drugs are 'magic mushrooms' (psylocibin) and 'acid' (LSD). A particular problem associated with hallucinogens is flashbacks, where the person re-experiences some of the perceptual effects of the drug when they have not been recently using it.

Ecstasy

Ecstasy (MDMA) (also known as "E") is a stimulant drug that also has hallucinogenic properties. Some young people use it at dance parties. The 2007 national Drug Strategy Household Survey found that 3.5% of Australians aged 14 or over had used ecstasy in the past year.[117] Users can develop an adverse reaction which in extreme cases can lead to death. To reduce this risk, users need to maintain a steady fluid intake, and take rest breaks from vigorous activity. While intoxicated, ecstasy users report that they feel emotionally close to others. When coming off the drug, they often experience depressed mood. The long-term effects of using ecstasy are of particular concern. There is considerable evidence that ecstasy damages nerve cells in the brain that use a chemical messenger called serotonin.[119] Research on people who have used ecstasy regularly shows that they have reduced sexual interest and a range of mental health problems.[120]

It is important to note that while ecstasy refers to the drug MDMA, people buying ecstasy may be buying pills hat contain other substances. This means that ecstasy users are risking the use of other drugs and poisonous substances.

There is very little research on the use or effects of cocaine, heroin, ecstasy or amphetamines on those with an intellectual disability. As previously mentioned, use is likely to be lower compared to those without an intellectual disability due to the level of independence that is required to obtain them. However, if used, side effects may be more severe due to the interaction with pre-existing medical or psychological disorders.

Inhalants

Inhalants are breathable chemical vapours that produce mind-altering effects. The effects of inhalants range from alcohol-like intoxication and euphoria to hallucinations, depending on the substance and the dosage. Use of inhalants also starves the brain of oxygen, causing a brief 'rush'. Inhalants may be solvents (e.g. paint thinners, petrol, glues), gases (e.g. aerosols, butane lighters), nitrites, and other substances. Although people are exposed to volatile solvents and other inhalants in the home and in the workplace, many do not think of inhalable substances as drugs because most of them were never meant to be used in that way. Young people are the most likely to abuse inhalants, partly because inhalants are readily available and inexpensive. In 2007, approximately 0.4% of people aged 14 or older used inhalants in the past year.[117]
The intentional misuse of common household products used by people who get high can be fatal, through 'sudden sniffing death' or as a result of long term use. Others become addicted to the inhalants. Young people are usually unaware of the serious health risks and those who start using them at an early age are likely to become dependent on them. These agents will destroy the cells in the brain, the liver and the kidneys.

Drug and alcohol use by people with an intellectual disability is relatively uncommon, and is often associated with other factors such as socialising with those who engage in antisocial or criminal activity. One Australian study comparing alcohol and drug use in offenders and non-offenders with a mild intellectual disability found that 20% of the offender group reported using inhalants at least once a month and 10% on a daily basis. Only one (3%) in the non-offender group reported using inhalants on a monthly basis.[121]

Tobacco

In 2007, tobacco was used by 19.4% of Australians aged 14 or older.[117] Tobacco is so widely used that we do not usually think of it as a mental health issue. However, there is a high rate of mental health problems in people who use tobacco. Smokers are around twice as likely to suffer from a mental illness compared to people who have never smoked.[3] Smoking is particularly high in people with schizophrenia (approximately 62%).[122] It is possible that tobacco is used as a type of self-medication by some people with mental illness in order to improve mood and cognitive functioning.

There is still not a clear picture of the prevalence of smoking among people with an intellectual disability and estimates vary from 1% to 36% of the population.[123,124] Anecdotal evidence suggests that older people with disability are more likely to smoke than those who are younger.

Risk factors for substance use disorders

Most of our knowledge about the risk factors for substance use disorders related to alcohol, but the risk factors for other drug use disorders are likely to be similar.

Risk factors for alcohol use disorders

There is not single cause of alcohol use disorders. Rather, there are many factors that increase a person's chances of developing such a disorder.[125]
Exploring the use of drugs among people with intellectual disability is a new field, however it seems that they use them for the same reasons as members of the general population.[126]
These include:

- ***Availability and tolerance of alcohol in society.*** Where alcohol is readily available and socially acceptable, alcohol use disorders are more likely to develop. This applies not only to society as a whole, but to particular social groups within a society.

- ***Alcohol use in the family.*** People who grow up in families where alcohol use is acceptable, where parents model use of alcohol and alcohol is readily available are more likely to develop an alcohol use disorder.[127, 128]

- ***Social factors.*** Certain groups are more prone to alcohol use disorders, including males, people with low education and income, people who have had broken marriages, and certain occupations with a drinking culture. For those with an intellectual disability, alcohol use can be a way of attempting to "fit in" and "feel normal" and secure acceptance by nondisabled fellow drinkers. The positive feeling associated with this can result in the person with an intellectual disability relying on and overusing alcohol.

- ***Genetic predisposition.*** People who have a biological parent with an alcohol use disorder are more likely to develop the disorder, even if adopted into a family with no alcohol use disorder.

- ***Alcohol sensitivity.*** Some people are physiologically less sensitive to the effects of alcohol than others and these people are more likely to drink heavily and develop an alcohol use disorder. There is some suggestion that those with an intellectual disability have lower tolerance to alcohol over time and that smaller amounts are needed to feel intoxicated. At the same time it seems to take less alcohol to produce social difficulties and health complaints.[129] This may be because an intellectual disability and associated difficulties magnify the effects of alcohol.

- ***Enjoyment from drinking.*** People can learn a habit of heavy drinking. This habit is maintained because alcohol has been associated with pleasant effects or a reduction of stress.

- ***Other mental health problems.*** People who have other mental health problems may use alcohol as a type of self-medication.

Interventions for substance misuse

Professionals who can help

A variety of health professionals can provide help to a person with substance use problems. If the person is uncertain about what to do, encourage and provide support if required for the person to consult a GP first. The GP might refer the person to a drug or alcohol service, or to a mental health professional if there are other mental health problems.

Treatments available for alcohol and drug problems

The treatments for problem substance use depend on the severity of the problem, how motivated the person is to change, and what other physical and mental health problems they also have. The following treatments are known to be effective.[130, 131]

For a person who is problem drinker or drug user

Brief intervention. If a person is drinking at a level that could damage their health or using drugs, then brief counselling by a GP can help them reduce or stop using. If they have a substance use disorder, it can help to motivate them to enter long-term treatment. This type of intervention generally takes 4 or fewer sessions, each lasting from a few minutes up to an hour. The GP looks at home much the person is using, gives information about risks to their health, advises them to cut down, discusses the advantages and disadvantages of changing and options for how to change, motivates the person to act by emphasising personal responsibility, and monitors progress. In doing these things, the GP adopts an empathic rather than coercive approach.

A person with an intellectual disability may need support from family, carer or support worker to attend the sessions. The GP may also require assistance in order to use appropriate communication strategies with the person.

For a person with a substance use disorder.

If the person has a substance use disorder, then treatment needs to do several things:

- Overcome any physiological dependence on alcohol or drugs,
- Overcome any psychological dependence (e.g. use of alcohol or drugs to help the person cope with anxiety or depression), and
- Overcome habits that have been formed (e.g. social life that revolves around drinking or drug use)

Good treatment should address all of the above. Depending on the nature and severity of the problem, it may involve:

Withdrawal management. If the person is dependent on alcohol or drugs, they will have to withdraw form the substance before other treatments commence. This should be done under professional supervision. However, withdrawal is not enough and should be combined with other treatments to prevent the person from relapsing. It is only part of the recovery process and many lifestyle changes are required to change behaviours associated with drinking or drug use.

Psychological treatments. These include:

- Cognitive behaviour therapy (which teaches the person to cope with craving and how to recognise and cope with situations that might trigger relapse). The degree to which the type of CBT needs to be adapted and the efficacy of it will depend on the person's level of disability, the problem it is being used to address and the professional's understanding of intellectual disability.
- Motivational enhancement therapy (which helps motivate and empower a person to change)
- Contingency management (this is used with people who misuse drugs and involves offering the person incentives such as shopping vouchers or privileges for negative drug test results or for harm reduction actions such as having a hepatitis or HIV test).

Medications. There are a number of types of medications that can assist a person to stay off substances. For people with an alcohol use disorder, these include anti-craving medication, medications that give an unpleasant effect if the person drinks or medications for the treatment of underlying anxiety and depression. For people dependent on Opioid drugs, methadone maintenance therapy is available.

Medications should be used where possible in combination with other interventions that provide the person with skills of life opportunities to manage their mental illness. Medications should be frequently reviewed by a GP or psychiatrist.

For a person with a substance use disorder and co-morbid mental illness

People with a substance use disorder often have another mental illness. The substance use may have started as a way to deal with emotional difficulties. This means that it is important that any other mental illness is treated as well, preferably at the same time.

Importance of early intervention for substance misuse

Substance use problems typically begin in adolescence and early adulthood, so this is the critical time for early intervention. This period may be delayed for people with an intellectual disability due to factors such as a later onset physical maturation and reduced access to substances. There is evidence that the brains of adolescents and young adults are still developing and are more sensitive to the effects of alcohol and other drugs than the brains of older adults.[132] Substance use during this period of life can affect brain development and lead to cognitive impairments. Early intervention will also prevent many of the long-term ill effects on a person's physical health, social relationships, education progress, financial status and job prospects. It will also reduce the possibility of serious problems with the law.

Crises associated with substance misuse

The main crises that may be associated with substance misuse are:

- The person has **severe effects from alcohol misuse**
- The person has **severe effects from drug misuse**
- The person is showing **aggressive behaviours**
- The person has **suicidal thoughts and behaviours**

Severe effects from alcohol misuse

If the person is using alcohol heavily, it is possible they will experience severe effects from alcohol intoxication, alcohol poisoning or alcohol withdrawal.

Alcohol intoxication substantially impairs the person's thinking and behaviour. When intoxicated the person may engage in a wide range of risk activities, such as having unprotected sex, getting into arguments or fights, or driving a car. The person may also be at higher risk of attempting suicide.

Alcohol poisoning is a dangerous level of intoxication that can lead to death. The amount of alcohol that causes alcohol poisoning is different for every person.

Alcohol withdrawal refers to the unpleasant symptoms a person experiences when they stop drinking or drink substantially less than usual. It is not simply a hangover. Unmedicated alcohol withdrawal may lead to seizures.

Severe effects from drug misuse

If the person is using drugs, it is possible they will experience severe effects from drug intoxication, drug overdose, or overheating or dehydration.

Drug intoxication can lead to impairment or distress, e.g. the person may have poor judgement, engage in risky behaviours of become aggressive. The effects vary depending on the type and amount of drug and also vary from person to person. It can be difficult to make a distinction between the effects of different drugs. Illicit drugs can have unpredictable effects as they are not manufactured in a controlled way.
Overdose occurs when the intoxication level leads to risk of death.

Overheating or dehydration can occur with prolonged dancing in a hot environment (such as a dance party) while on some drugs (e.g. ecstasy) without adequate water intake. This causes the person's body temperature to rise to dangerous levels.

Aggressive behaviours

There is an increased risk of aggression to others for people who experience substance use disoders.[97] Twice as many crimes are committed by people who are intoxicated with alcohol or other drugs.

Suicidal thoughts and behaviours

There is also increased risk of suicide. Of people who have a substance use disorder in the past 12 months, approximately 3% attempt suicide compared to 0.4% in the population as a whole.[54] Of all persons who complete suicide, 26% gave a substance use disorder.[74]

Suicidal thinking and high risk taking behaviour in those with an intellectual disability should always be investigated. The method chosen by a person with an intellectual disability may not have any lethal potential but may have been chosen because the person believed it would be fatal, so the intent is still there.[12]

Mental Health First Aid Action Plan for People with an Intellectual Disability and Substance Misuse [133-135]

1. **Approach the person , assess and assist with any crisis**
2. **Listen non-judgementally**
3. **Give support and information**
4. **Encourage and support the person to get appropriate professional help.**
   The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered
5. **Encourage other supports.**
   The person with an intellectual disability may need assistance to do this

ACTION 1:
Approach the person, assess and assist with any crisis

How to approach

If you are concerned about someone's substance misuse, talk to the person about it openly and honestly. Before speaking with the person, reflect on their situation, organise your thoughts and decide what you want to say. Arrange a time to talk with the person. Talk with them in a quiet, private environment at a time when there will be no interruptions, when both of your are sober and are in a calm frame of mind. Express you concerns non-judgementally in a supportive, non-confrontational way. Be assertive, but do not blame or be aggressive.

Consider the following when making your approach:

- ***The person's own perception of their using***. Try to understand the person's own perception of their using. Ask the person about their substance use (for example, about how much of the substance the person is using) and if they believe their substance use is a problem.

- ***The person's readiness to talk.*** Consider the person's readiness to talk about their substance us problem by asking about areas of their life that it may be affecting, for example, their mood, work performance and relationships. Be aware that the person may deny, or might not recognise, that they have a substance use problem and that trying to force the person to admit they have a problem may cause conflict.

- ***Use 'I' statements***. Express your point of view by using 'I' statements, for example, "I am concerned about how much you've been drinking lately" rather than 'you' statements such as "you have been drinking too much lately".

- ***Rate the act, not the person***. Identify and discuss the person's behaviour rather than criticise their character, for example, "Your drug use seems to be getting in the way of your friendships" rather than "You're a pathetic druggie".

- ***The person's recall of events***. When discussing the person's substance use, bear in mind the person may recall events that occurred while they were using in a different way to how they actually happened, or that they may not recall events at all. This may be a little more difficult with a person who has an intellectual disability as they may already have memory or recall deficits due to their disability.

- ***Stick to the point.*** Focus on the person's substance use and do not get drawn into arguments or discussion about other issues. As you talk with the person, be on the lookout for any indications that the person may be in crisis.

*If you have concerns that the person has acute **effects of alcohol misuse** (intoxication, alcohol poisoning or sever withdrawal), find out how to **assess** and **assist** this person in Section 3.6 First Aid for Acute effects of Alcohol Misuse.*

*If you have concerns that the person has an **acute effects of drug misuse** (drug intoxication,*

*overdose, overheating or dehydration), find out how to **assess** and **assist** this person in Section 3.7 First Aid for Acute Effects of Drug Misuse.*

*If you have concerns that the person is showing **aggressive behaviours**, find out how to **assess** and **assist** this person Section 3.8 First Aid for Aggressive Behaviours.*

*If you have concerns that the person may be having **suicidal thoughts and behaviours,** find out how to **assess** and **assist** this person in Section 3.1 First Aid for Suicidal thoughts and Behaviours.*

If you have no concerns that the person is in crisis, you can ask them about how they are feeling and how long they have been feeling that way and move on to ACTION 2.

When asking questions of a person with an intellectual disability it is important to:

- Communicate in a way that will assist them to understand e.g. by using visual aids,
- Check they have understood what you are asking by getting them to tell you in their own words, pictures, signs what they think you are asking them.
- Avoid asking leading questions.
- Be aware that people with an intellectual disability will often answer in the affirmative in order to please or appear capable so check that what they say is what they really mean.

ACTION 2:
Listen non-judgementally

See Action 2 in Section 2.1 *Depression* for more tips on non-judgemental listening. Below are some specific points that apply to talking with someone with substance misuse.

- Treat the person with respect and dignity

- Interact with the person in a supportive way, rather than threatening, confronting or lecturing them.

- Listen to the person without judging them as bad or immoral. Be empathetic to their concerns and provide comfort where possible.
- Avoid expressing moral judgements about their substance use

- Do not criticise the person's substance use. You are more likely to be able to help them in the long term if you maintain a non-critical but concerned approach. People with an intellectual disability are frequently told what to do and substance use may be a way of obtaining some autonomy or escaping. Criticism may merely reinforce some of the issues that may have led towards the substance abuse.

- Do not label the person e.g. by calling them a "druggie" or "alcoholic"

- Try not to express you frustration at the person for having substance use problems. Privately acknowledge your anger or frustration and work through it.

When listening to a person with an intellectual disability you may need to use more checking questions and paraphrasing to ensure that you have understood correctly. It is far better to ask the person to repeat what they said, or to say it in a different way than to pretend that you have understood them or to assume that they have understood you.

ACTION 3:
Give support and information

Ask the person if they would like information about substance misuse or any associated risks. If they agree, provide them with relevant information.
Try to find out whether the person wants help to change their substance misuse. If they do, offer your help and discuss what you are willing and able to do. Have the phone number for an alcohol and other drug helpline and perhaps the address of a reputable website with you to offer them (see Helpful resources at the end of this chapter).

For people with an intellectual disability information and support needs to be given in a way that will promote understanding, e.g. Keep sentences short and simple and don't use jargon; write or draw ideas on paper for them. Check their understanding by asking them to tell you in your own words or way what you have just told them.
They may also need help with reading and understanding the content of any written information. This assistance should be provided in a non-judgemental and motivational way to help the person want to quit.
Information and education on substance misuse should be made available to staff and carers so they can provide appropriate and ongoing support.

Have realistic expectations for the person

Do not expect a change in the person's thinking or behaviour right away. Bear in mind that:

- Changing substance use habits is not easy

- A person's willpower and self-resolve is not always enough to help them stop problem substance use

- Giving advice alone may not help the person change their substance misuse.
- A person may try to change or stop their substance use more than once before they are successful
- If abstinence from drinking is not the person's goal, reducing the quantity of alcohol consumed is still a worthwhile objective.

The stages of change[136]

A person who is misusing substances may not be ready to change. Major behaviour changes take time to be achieved and often involve the person going through a number of stages. There are five stages of change, and the person may move back and forth between the stages at different times. The information and support you offer to the person can be tailored to their level of readiness as shown below:

The stages of change

Stage 1: Pre-contemplation – the person does not think they have a problem.
Give the person information about the substance and how it might be affecting them, discuss less harmful ways of using the drug and how to recognise overdose.

Stage 2; Contemplation – the person thinks their substance use might be a problem
Encourage the person to keep thinking about quitting, talk about the pros and cons about changing, give information and refer them to a professional. Poorer problem solving abilities of people with an intellectual disability make it likely that they will need significant support to see that the disadvantages of their substance use may outweigh the advantages.

Stage 3: Preparation – the person has decided to make a change
Encourage the person and support their decision to change, and help them plan how they will stop using substances (e.g. talk to a substance use counsellor or GP)

Stage 4: Action – making the change
Provide support by helping the person develop strategies for saying 'no' and avoiding people who use substances, practicing doing other things when they feel like using substances and finding other easy to cope with distress. Encourage the person to get periodic health checks.

Stage 5: maintenance – keeping up the new habits
Support the person to keep up the new behaviour. Focus on the positive effects of not using substances and praise their achievements.

A person may relapse once or several times before making long term changes to their substance misuse.
Because there are number of additional life problems for a person with intellectual disability (e.g. escaping from abusive situations, protecting themselves from victimization, finding employment, self-care, social skills training, legal rights, and building peer networks) they are at greater risk for relapse and often need types of treatment, training, and supports that are tailored to their needs.[137]

Supporting the person who does want to change

Tell the person what you are willing and able to do to help. This may range from simply being a good listener to organising professional help. See below for specific ways to help a person who wants to change their problem drinking. Some of these suggestions are helpful for a person with other types of substance misuse.

Encouraging low-risk drinking

To encourage low-risk drinking, the following may assist the person to change their drinking behaviours:

- Help them to realise that only they can take responsibility for reducing their alcohol intake and that although changing drinking patterns is difficult, they should not give up trying.
- Encourage and assist the person to find some information on how to reduce the harms associated with their problem drinking
- If appropriate, inform the person that alcohol may interact with other drugs (illicit, prescribed, or over-the-counter) in an unpredictable way which may lead to a medical emergency
- Ask the person if they would like some tips on low-risk drinking.

If the person wants to change their drinking behaviour, suggest some of the following tips for low-risk drinking.

Tips for low risk drinking

- Know what a standard drink is and be aware of the number of standard drinks they consume
- Know the alcohol content of their drink
- See if the number of standard drinks is listed on the beverage's packaging
- Eat while drinking

- Drink plenty of water on a drinking occasion to prevent dehydration
- Drink beverages with lower alcohol content, e.g. drinking light beer instead of full strength beer
- Switch to non-alcoholic drinks when they start to feel the effects of alcohol
- Do not let people top up your drink before it is finished, so as not to lose track of how much alcohol they have consumed
- Avoid keeping up with your friends drink for drink.
- Avoid drinking competitions and drinking games
- Drink slowly, for example, by taking sips instead of gulps and putting their drink down between sips
- Have one drink at a time
- Spend your time in activities that don't involve drinking
- Make drinking alcohol a complementary activity instead of the sole activity
- Identify situations where drinking is likely and avoid them if practical.

There is often social pressure to get drunk when drinking. Encourage the person to be assertive when they feel pressured to drink more than they want or intend to. Tell the person that they have the right to refuse alcohol. Tell them that they can say "no thanks" without explanation, or suggest different ways they can say "no" such as "I don't feel like it", "I don't feel well" or "I am taking medication". Encourage the person to practice different ways of saying "No". Suggest to the person that saying "no" to alcohol gets easier the more they do it and that the people who care about hem will accept their decision not to drink or to reduce the amount that they drink.

Supporting the person who does not want to change

If a person does not want to reduce or stop their substance use, you cannot make them change. Given the benefits that substance use may provide for a person with an intellectual disability (e.g. escape, self-medication, socialisation, a sense of feeling normal) suggestion of change can be met with great resistance.

It is important that you maintain a good relationship with the person as you may be able to have a beneficial effect on their use.

Let the person know you are available to talk in the future. You can speak with a health professional who specialises in substance misuse to determine how best to approach the person about your concerns, or you could consult with others who have dealt with such problems about effective ways to help the person. You could discuss with the person the link between their substance use and the negative consequences they are experiencing.

What isn't supportive

If the person is unwilling to change their substance use, do not"

- Feel guilty or responsible
- Join in using substances with the person
- Use negative approaches (e.g. lecturing or making them feel guilty) as these are unlikely to promote change
- Try to control the person by bribing, nagging, threatening or crying
- Make excuses for the person or cover up their substance use or related behaviour
- Take on the person's responsibilities except if not doing so would cause harm, e.g. to their own or other's lives.
- Deny their basic needs, e.g. food or shelter

If the person continues to misuse substances, you should encourage them to seek out information (e.g. reputable websites or pamphlets) about ways to reduce risks associated with alcohol or other drug use. If the person is using or planning to use alcohol or other drugs while pregnant or breastfeeding, encourage them to consult with an appropriate health professional.

ACTION 4:
Encourage and support the person to get appropriate professional help

Many people with alcohol and drug problems do not receive health or other serves for these problems. In Australia, only 24% of the people who had a substance use disorder in the past year received such help.[6] A failure to seek help can cause problems with family and employment, damage physical health and increase the risk of developing other mental illnesses such as depression and anxiety disorders.

Discuss options for seeking professional help.

Tell the person that you will support them in getting professional help. If the person is willing to

seek professional help, give them information about local options and encourage them to make an appointment.

The person with an intellectual disability may need additional support to link them with appropriate professional help. A professional will require good information about the person with an intellectual disability so it is important to involve a support person who knows the person well.

You may need to stay with them longer, or if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access this professional. Pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.[21]

It is important to take with you to any professional's appointment information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

There are very few drug and alcohol specialists who also have experience in working with those with an intellectual disability. Therefore it is advisable that a carer or support person work closely with the drug and alcohol professional so treatments can be best adapted to the skills and capacity of the client.

What if the person doesn't want professional help?

Be prepared for a negative response when suggesting professional help. The person may not want such help when it is first suggested to them and may find it difficult to accept. Stigma and discrimination can be barriers to seeking help. If this is the case, explain to the person that there are several approaches available for treating substance use problems. If the person won't seek help because they don't want to stop using completely, explain that the treatment goal may be to reduce consumption rather than to quit altogether. Reassure the person that professional help is confidential.

If the person is still unwilling to seek professional help, you should set boundaries around what behaviour you are willing and not willing to accept from the person. It is important to continue to suggest professional help to the person. However, pressuring the person or using negative approaches may be counter-productive.

Be prepared to talk to the person about seeking professional help again in the future. Be compassionate and patient while waiting for the person to accept they need professional help – it is ultimately the person's decision. Changing substance misuse is a process that can take time. Remember that the person cannot be forced to get professional help except under certain circumstances, for example, if a violent incident results in the police being called or following a medical emergency.

ACTION 5:
Encourage other supports

Inform the person of support they may find useful and allow the person to decide which they prefer.

Self-help strategies

There are websites that allow a person to screen themselves for alcohol problems and which encourage the person to change (see Helpful Resources at end of chapter). There is evidence that such websites can be effective.[138]
If these seem appropriate and helpful for a person with an intellectual disability he or she may need help from a support worker, friend or family member.

The person with an intellectual disability may have few if any self-help strategies due to their reduced cognitive abilities, lack of experience and education.
Disability-specific services may offer specialised education programs to assist people to learn self-help strategies and generalise these into their every day life. It is useful to contact the state government disability service in your locality for information about what is available.

If the person with an intellectual disability does have some strategies, they may need a reminder as to what they are, and then additional support to put these into practice.

Role of family and friends in recovery

Research has shown that people are more likely to recover if:[139]

- They have stable family relationships
- They are not treated with criticism and hostility by their family or carers.
- They have supportive friends
- Their friends do not use alcohol or drugs themselves and they encourage the person not to use.

Family and friends and for people with an intellectual disability their carers or direct support workers, can play an important role in the recovery of a person with an alcohol or drug problem (see Box). Encourage the person to

reach out to friends and family who support their efforts to change their substance use behaviours and to spend time with supportive non-using friends and family. Family and friends can help the person to seek treatment and also support them to change their substance behaviour. They can also help reduce the changes of a relapse after a person has stopped substance use. People are more likely to start using again if there is an emotional upset in their life and family and friends can try to reduce this possibility. It is useful to warn the person that not all family and friends will be supportive of their efforts.

In looking to family and friends, of the person with an intellectual disability for support, it is important to keep in mind that they may be under stress or 'burnt out' due to their burden of care.

There are numerous groups that support individuals who are recovering from substance use by providing mutual support and information, including self-help groups in which people work to follow steps to recovery (e.g. Alcoholics Anonymous and Narcotics Anonymous). Research shows that these groups can be beneficial.[140] There are also support groups for families of people affected by substance use disorders, such as Al-Anon and Alateen.
While groups for substance users might not be suitable for the majority of people with an intellectual disability, they should not be ruled out as a source of help. It is worth contacting the organiser of such a group to explore the possibilities for the person with an intellectual disability whom you are concerned about.

- Other strategies or suggestions for people with an intellectual disability include:

- Encouraging the person to get involved in activities that are inconsistent with using drugs or alcohol. Possible suggestions include going to venues where alcohol or drugs are not available or playing sport where the adverse effects of alcohol or drugs on performance may be highlighted.

- Encourage the person to engage in activities at times that would make substance use difficult. (e.g. planning events that the person enjoys at times just before they would likely go out to look for substances or use them)

- Support the person in engaging with peers who do not use substances. This can be helpful because often people use substances as a way of socialising.

- Explore the possibility that the misuse may be due to an underlying mental disorder and then support the person in receiving treatment for this.

- Support the person in developing skills that may reduce substance use or relapse. This might include social skills training or assertiveness training to resist offers by others to start up again.

HELPFUL RESOURCES
for substance misuse

Screening for substance use disorders

Questionnaires to screen for substance use disorders are available on the internet. These give feedback on whether a person is likely to have a substance use disorder and motivate the person to change. If these seem appropriate and helpful for a person with an intellectual disability he or she may need help from a support worker, friend or family member.
Research has shown that the following website is effective in motivating change for people with alcohol problems.[138]
www.checkyourdrinking.net

The following website gives screening questionnaires for drug use disorders:
www.drugscreen.org

Websites

Australian Drug Foundation
http://www.adf.org.au

The Australian Drug Foundation (ADF) is an independent, non-profit organisation working to prevent and reduce alcohol and drug problems in the Australian community. Its website is a good source of factual information on most types of drugs used illegally or unsafely.

Australian Drug information network (ADIN)
http://www.adin.com.au

This site is funded by the Australian Department of Health and Ageing to provide a central point of access to Australian drug and alcohol information.

National Drug and Alcohol Research Centre (NDARC)
http://www.med.unsw.edu.au/ndarc

NDARC is based at the University of New South Wales and is funded by the Commonwealth Government. Its aim is to increase the effectiveness of treatment for drug and alcohol problems in Australia. Its website has information and online ordering for some excellent booklets on different drug information.

Drug Information
http://www.drugsinfo.nsw.gov.au

This website describes the NSW Government drug strategy. It also provides fact sheets on illicit drugs, legal information, online publications and links to international drug websites.

Australian National Tobacco Campaign
http://www.quitnow.info.au

This website gives online information and advice on quitting smoking.

Australian Government Alcohol Information
http://www.alcohol.gov.au

This website gives information on alcohol-related health, science, news and government policy.

Highsnlows
www.highsnlows.com.au

This website was set up by the Victorian Government, in association with the national Cannabis Prevention and Information Centre (NCPIC) to provide information about the link between cannabis and mental health. It includes animations, fact sheets and a discussion forum.

Telephone Services

Counselling online
www.counsellingonline.com.au

Counselling Online is a service where a person can communicate with a professional counsellor about an alcohol or drug related concern, using live chat or email. It is provided by Turning Point, a substance use treatment centre. This service is free for anyone seeking help with their own drug use or the drug use of a family member, relative or friend. Counselling Online is available 24 hours a day, 7 days a week, across Australia.

Quitline

National smoking quitline, 24 hours a day
Phone 131 848
http://www.quit.org.au

Alcohol and Drug Information Services (ADIS)

These services are available across Australia, 24 hours a day and will try to answer any questions about alcohol, tobacco or other drugs.

Queensland
(07) 3236 2414, freecall 1800 177 833

New South Wales
(02) 9361 8000, freecall 1800 422 599

Victoria
Phone (03) 9416 1818, freecall 1800 888 236

Western Australia
(08) 9442 5000, freecall 1800 198 024

Australian Capital Territory
(02) 6205 4545

Northern Territory
(08) 8922 8399, freecall 1800 131 350

South Australia
freecall 1300 131 340

Tasmania
(03) 6222 7511, freecall 1800 811 994

National
1300 368 186 (Family Drug Support)
http://www.fds.org.au

Cannabis Information and Helpline
Freecall nationally: 1800 30 40 50
2pm-11pm Sunday-Friday

Book

Fletcher Am (2001). *Sober for good: new solutions for drinking problems – advice from those who have succeeded.* Houghton Mifflin, New York, NY, USA.

Based on interviews with over 200 recovered problem drinkers, this book give guidance about different paths to recovery, whether the goal is abstinence or occasional use. It also includes advice for friends and family on helping someone who is reluctant to change.

Support Groups

Alcoholics Anonymous and Narcotics Anonymous
http://www.alcoholicsanonymous.org.au
http://www.naoz.org.au

These organisations provide mutual support groups for people recovering from substance use disorders. The websites give contacts for groups in any part of Australia.

Al-Anon and Alateen
http://www.al-anon.org/australia/

This organisation provides information and support for the family members and friends of alcoholics. The website gives details of meetings in all states and territories.

SECTION 3

First Aid for Mental Health Crises and Intellectual Disability

Sunset

Section 3:

First Aid for Mental Health Crises and Intellectual Disability

Introduction

This section contains recommendations for members of the public on how to assess and assist in a number of mental health crisis situations. Some of these crises can occur in people with mental illness or those who are in emotional distress. Others may precipitate the onset of a mental illness, or may be related to substance misuse. The role of the first aider is to assist the person until appropriate professional help is received or the crisis resolves.

The first aid advice in this section is based on international guidelines that have been developed using the expert consensus of panels of mental health consumers, carers and clinicians. These experts came from a range of developed English speaking countries: Australia, Canada, Ireland, New Zealand, the UK and USA.

Each individual is unique and it is important to tailor your support to that person's needs. These recommendations therefore may not be appropriate for every person who may be in crisis. Crises vary in severity and the first aid given also varies. If the crisis is severe enough to require emergency professional help, then your role as a first aider finishes when you hand over to the professional If the crises is less severe, the first aid can continue with other actions from the Mental Health First Aid Action Plan after the crisis resolves.

It is important for the mental health first aider supporting a person who also has an intellectual disability to read and be familiar with the strategies and techniques outlined in section 1, 1.2 *Mental Health First Aid and Intellectual Disability* (*General tips when working with those with intellectual disability and mental health problems.*)

First aid recommendations are provided for the following crisis situations:

3.1 Suicidal thoughts and behaviours

3.2 Non-suicidal self-injury

3.3 Panic attacks

3.4 Traumatic events

3.5 Severe psychotic states

3.6 Severe effects from alcohol misuse

3.7 Severe effects from drug misuse

3.8 Aggressive behaviours

3.1 First Aid for Suicidal Thoughts and Behaviours

Geisha

3.1 First Aid for Suicidal Thoughts and Behaviours[141, 142]

An important note

Self–injury can indicate a number of different things. Someone who is hurting themselves may be at risk of suicide. Others engage in a pattern of self-injury over weeks, months or years and are not necessarily suicidal.

This advice can be of use to you only if the person you are helping is suicidal. If the person you are assisting is injuring themselves, but is not suicidal, please refer to Section 3.2 *First Aid for Non-suicidal Self-injury.*

Facts on suicide in Australia

A national survey of Australians aged 16-85 found that 3.2% had attempted suicide at some time in their life and 0.4% had attempted suicide in the past year.[54] In 2007, suicide took the lives of 1881 Australians. [144] This is higher than the number of deaths from motor vehicle accidents. Males accounted for 77% of suicides. Among males, those aged 35-39 years had the highest rate of suicide and those aged 15-19 years the lowest. After the age of 39 years, the rates then dropped gradually until the age of about 75, after which they increased again. Amongst females, suicide rates did not vary greatly across age groups. Approximately 87% of people who complete suicide have a mental illness.[74] Whilst risk factors for suicide are higher among people with an intellectual disability it appears that the rates are lower than the general population.[143]

How to assess

Suicidal thinking and high risk taking behaviour in those with an intellectual disability should always be investigated. The method chosen by a person with an intellectual disability may not have any lethal potential but may have been chosen because the person believed it would be fatal, so the intent is still there.[12] Research has found that the seriousness of the suicidal behaviour does not always link with the level of intention to die. This may be more pronounced amongst people with an intellectual disability due to their inability to link cause and effect and greater impulsivity.[143]

Important signs that a person may be suicidal are:[145]

- Threatening to hurt or kill themselves
- Looking for ways to kill themselves; seeking access to pills, weapons, or other means
- Talking, drawing or writing about death, dying or suicide
- Hopelessness
- Rage, anger, seeking revenge
- Acting recklessly or engaging in risk activities, seemingly without thinking
- Feeling trapped, like there's no way out
- Increasing alcohol or drug use
- Withdrawing from friends, family or society
- Anxiety, agitation, unable to sleep or sleeping all the time
- Dramatic changes in mood
- No reason for living, no sense of purpose in life.

People may show one or may of these signs and some may show signs not on this list.

If you have seen some warning signs of the person feeling suicidal, engage the person in discussion about your observations. If you suspect someone may be at risk of suicide, let the person know that you are concerned about them and are willing to help. It is important to ask them directly about suicidal thoughts. Do not avoid using the word 'suicide'. It is important to ask the question without dread, and without expressing a negative judgement. The question must be direct and to the point. For example, you could ask:

- **"Are you having thought of suicide?" or**
- **"Are you thinking about killing yourself?"**

The person with an intellectual disability may not understand the term 'suicide'. You may need to use the words such as "kill yourself" or 'make yourself die" instead. Use concrete terms, and avoid words with double meanings or idioms. Remember to check their understanding by asking them to explain in their own words what they have heard.
People with an intellectual disability may often want to give you what they think is the "right" answer. Therefore they may say "yes" when in fact the answer is "no" or vice versa. It is important to tell them that you want to hear how they are really feeling and that you are not there to judge them. You're there to help them either way.

If you appear confident in the face of the suicide crisis, this can be reassuring for the suicidal person. Although some people think that asking about suicide can put the idea in the person's

mind, this is not true. Another myth is that someone who talks about suicide isn't really serious. Remember that talking about suicide may be a way for the person to indicate just how badly they are feeling.

How to assist

How should I talk with someone who is suicidal?

It is important to:

- Tell the suicidal person that you care and that you want to help them
- Express empathy for the person and what they are going through
- Clearly state that thoughts of suicide are often associated with a treatable mental illness, as this may instil a sense of hope for the person.
- Tell the person that thoughts of suicide are common and do not have to be acted on.

Suicidal thought are often a plea for help and a desperate attempt to escape from problems and distressing feelings. You should encourage the suicidal person to do most of the talking, if they are able to. They need the opportunity to talk about their feelings and their reasons for wanting to die and may feel great relief at being able to do this. It may be helpful to talk about some of the specific problems the person is experiencing. Discuss ways to deal with problems which seem impossible to cope with, but do not attempt to 'solve' the problems yourself.

How can I tell if the situation is serious?

First, you need to determine whether the person has definite intentions to take their life, or whether they have been having more vague suicidal thoughts such as 'what's the point of going on?' To do this, you need to ask the person if they have a plan for suicide. The three questions you need to ask are:

1. Have you decided how you would kill yourself?

2. Have you decided when you would do it?

3. Have you taken any steps to secure the things you would need to carry out your plan?

A higher level of planning indicates a greater risk. However, you must remember that the absence of a plan is not enough to ensure the person's safety. All thought of suicides must be taken seriously.

Also you need to be aware that people with an intellectual disability may have difficult answering your questions. You may need to use more simple language or consider the use of visual aids. You may need also to ask a support person who is with them if they are concerned about suicide risk, and survey their environment for evidence. It is good practice to collect as much information as you can to ensure that your assessment of the situation is accurate so that you can offer the right type of help.[38]

Next, you need to know about the following extra risk factors:

- Has the person been using alcohol or other drugs? The use of alcohol or other drugs can make a person more susceptible to acting on impulse.

- Has the person made a suicide attempt in the past? A previous suicide attempt makes a person more likely to make a future suicide attempt or to kill themselves.

Once you have established that the risk of suicide is present, you need to take action to keep the person safe.

How can I keep the person safe?

A person who is actively suicidal should not be left on their own. If you can't stay with them, you need to arrange for someone else to do so. In addition, give the person a safety contact which is available at all times (such as a telephone help line, a friend or family member who has agreed to help, another carer or a professional help give).

Emergency Help Lines

Lifeline 24-Hour Counselling 13 11 14

Suicide Call Back Service 1300 659 467

It is important to help the suicidal person to think about people or things that have supported them in the past and find out if these supports are still available. These might include a doctor, psychologist or other mental health worker, disability worker, family member or friend, or a community group such as a club or church.

Do not use guilt and threats to prevent suicide. For example, do not tell the person they will go to hell or ruin other people's lives if they die by suicide.

What about professional help?

During the crisis

Mental health professionals advocate always asking for professional help, especially if the person has symptoms of psychosis. If the suicidal person has a weapon or is behaving aggressively towards you, you must seek assistance from the police in order to protect yourself. However, the

person you are helping may be very reluctant to involve a professional and if the person is close to you, you may be concerned about alienating them. In fact, some people who have experienced suicidal thoughts or who have made plans for suicide feel that professional help is not always necessary.

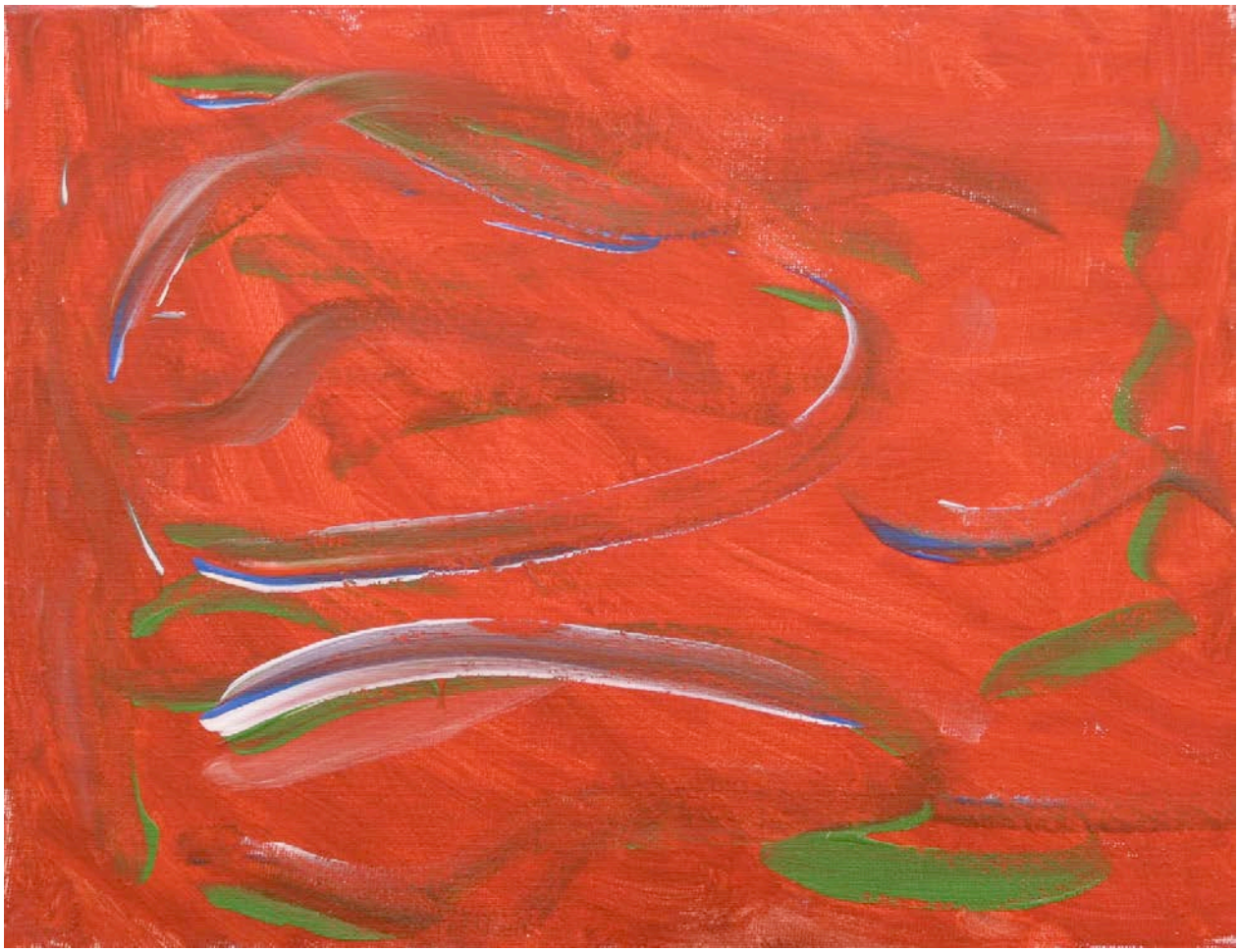
After the crisis has passed
After the suicide crisis has passed, ensure the person gets whatever psychological and medical help they need. Other parts of this manual may be useful for you in achieving this.

What if the person makes me promise not to tell anyone else?
You should never agree to keep a plan for suicide a secret. However, you should respect the person's right to privacy and involve them in decisions regarding who else knows about their suicidal intentions.

The person I am trying to help has injured themselves, but insists they are not suicidal. What should I do?
Some people injure themselves for reasons other than suicide. This may be relieve unbearable anguish, to stop feeling numb, or other reason. People with an intellectual disability, especially those with more significant levels, often engage in self injurious behaviour (SIB). Very commonly, SIB is a result of the person's inability to communicate their boredom, loneliness, anger, or physical pain to others. This can be distressing to see. Section 3.2 *First Aid for Non-suicidal Self-injury* can help you to understand and assist if this is occurring.

A final note
Do your best for the person you are trying to help. Remember, though, that despite our best efforts, some people will still die by suicide.

3.2 First Aid for Non-suicidal Self-injury



Red Abstract

3.2 First Aid for Non-suicidal Self-injury[146, 147]

An important note

This first aid advice applies only if the person is injuring themselves for reasons other than suicide. If the person you are assisting is injuring themselves and is suicidal, please refer to Section 3.1 *First Aid for Suicidal thoughts and Behaviours.*

Some people engage in non-suicidal self-injury even when suicidal. This means that even though they are having thoughts of suicide, their self-inflicted injuries are not intended to result in death.

Some people say that engaging in non-suicidal self-injury helps them to avoid acting on suicidal thoughts. People with an intellectual disability, especially those with more significant levels, often engage in self injurious behaviour (SIB). Very commonly, SIB is a result of the person's inability to communicate a range of emotions, needs and wants.
If the person is engaging in non-suicidal self-injury and is suicidal, you will need to refer to both Sections 3.1 and 3.2.

Facts on non-suicidal self-injury

Many terms are used to describe self-injury, including self-harm, self-mutilation, cutting and parasuicide. There is a great deal of debate about what self-injury is and how it is different to suicidal behaviour. Here the term *non-suicidal self-injury* is used to refer to situations where the self-injury is not intended to result in death. It is not always easy to tell the difference between non-suicidal self-injury and a suicide attempt. The only way to know is to ask the person directly if they are suicidal. Keeping in mind that for a person with an intellectual disability you may need to use different words, i.e., more concrete terms and visual aids if appropriate. (see page 93)

People who engage in non-suicidal self-injury do so for many reasons. These include:

- **To manage painful feelings**
- **To communicate a range of emotions they may be unable to verbally, e.g. frustration, anger, confusion, excitement, boredom, loneliness**
- **To punish themselves**
- **To exert influence over others or their environment**
- **To end feelings of dissociation (feelings of unreality or being detached from themselves)**
- **To manage or communicate physical pain if they are unable to express it verbally**
- **To avoid or combat suicidal thoughts**
- **Sensation seeking**
- **To reaffirm personal boundaries and exert control over the body**
- **As a result of an associated genetically determined syndrome in some people with an intellectual disability. E.g. Cri du Chat syndrome, Cornelia de Lange syndrome, Rett syndrome.**

There are no Australian statistics on the frequency of non-suicidal self-injury in the general population. However, a UK survey found that 2-3% of people aged 16-74 reported non-suicidal self-injury in the past 12 months. The rate was highest in young people, but was found to occur in all age groups.[148] Recent research from the UK regarding self-injury in people with intellectual disability found rates ranging from 3%-24% in the intellectually disabled population.[149] It is generally accepted that the prevalence of self-injurious behaviours increases with the severity of disability.

How to assess

If you suspect that someone you care about is deliberately injuring themselves, you need to discuss it with them. Do not ignore suspicious injuries you have noticed on the person's body.

There are many different types of non-suicidal self-injury you may observe. These include:[150]

- Cutting, scratching, or pinching skin, enough to cause bleeding or a mark which remains on the skin
- Banging or punching objects or self to the point of bruising or bleeding
- Ripping and tearing skin
- Carving words or patterns into skin
- Interfering with the healing of wounds
- Burning skin with cigarettes, matches or hot water
- Compulsively pulling out large amounts of hair
- Deliberately overdosing on medications when this is NOT meant as a suicide attempt.

In addition to those listed above, common types of self-injury in people with an intellectual disability include:

- head hitting
- self biting
- eye gouging
- repeated vomiting
- eating non-edible substances (pica)

How to assist

How should I talk with someone who is deliberately injuring themselves?

Let the person know that you have noticed the injuries. Aid expressing a strong negative reaction to the self-injury and discuss it calmly with the person. It is important that you have reflected on your own state of mind and are sure you are prepared to calmly deal with their answer when asking the person about their self-injury.

Understand that self-injury is a coping mechanism, and therefore, 'stopping self-injury' should not be the focus of the conversation. Instead, look at ways to relieve the distress. Do not trivialise the feelings or situations which have led to the self-injury. Do not punish the person, especially by threatening to withdraw care.

What should I do if I witness someone deliberately injuring themselves?

If you have interrupted someone in the act of self-injury, intervene in a supportive and non-judgemental way. Remain calm and avoid expressions of shock or anger. Express you concern for the person's wellbeing. Ask whether you can do anything to alleviate the distress. Ask if any medical attention is needed.

What about professional help?

Medical emergency

If the person has harmed themselves by taking an overdose of medication or consuming poison, call an ambulance as the risk of death or serious harm is high. Deliberate overdose is more frequently intended as a suicide attempt, but is sometime a form of self-injury. Regardless of the person's intentions, emergency medical help must be sought.

If the injury is life-threatening, emergency medical help must be sought. Emergency services should always be called if the person is confused, disorientated or unconscious, or if they have bleeding that is rapid or pulsing.

Obtaining mental health care

You should encourage and support the person to seek professional help. Self-injury is not an illness in itself, but is usually a symptom of either a mental illness or serious psychological distress which needs treatment. Ensure that the person knows where professional mental health care is available, but do not force them to use it if they are unwilling.

Further information about encouraging a person to seek professional treatment can be found in Section 2 of this manual.

How can I keep the person safe?

Encourage the person to speak to someone they trust the next time they feel the urge to injure themselves. Also, ensure that adequate first aid supplies are accessible to the person.

3.3 First Aid for Panic Attacks

Windy Day

3.3 First Aid for Panic Attacks[151, 152]

Facts on panic attacks

More than one in four people have a panic attack at some time in their life.[73] Few on to have repeated attacks, and fewer still go on to develop panic disorder or agoraphobia. Although anyone can have a panic attack, people with anxiety disorders are more prone.

Some panic attacks do not appear to be triggered by anything specific. These are called 'uncued' panic attacks. Other panic attacks may be associated with a feared situation. For example, a person with social phobia may experience a panic attack in a social setting.

How to assess

Signs and symptoms of a panic attack[2]

A panic attack is a distinct episode of high anxiety, with fear or discomfort, which develops abruptly and has its peak within 10 minutes. During the attack, several of the following symptoms are present.

- Palpitations, pounding heart, or rapid heart rate.
- Sweating
- Trembling and shaking
- Shortness of breath, sensations of choking or smothering
- Chest pain or discomfort
- Abdominal distress or nausea
- Dizziness, light-headedness, feeling faint or unsteady
- Feelings of unreality or being detached from oneself.
- Fears of losing control or going crazy
- Fear of dying
- Numbness or tingling
- Chills or hot flushes

If someone is experiencing the above symptoms and you suspect that they are having a panic attack, you should first ask them if they know what is happening and whether they have ever had a panic attack before. If asking a person with an intellectual disability you may need to ask this question by referring to the sensations rather than the words "panic attack".

How to assist

What should I do if I think someone is having a panic attack?

If the person says that they have had panic attacks before, and believe that they are having one now, ask them if they need any king of help, and give it to them. If you are helping someone you do not know, introduce yourself.

What if I am uncertain whether the person is really having a panic attack, and not something more serious like a heart attack?

The symptoms of a panic attack sometimes resemble the symptoms of a heart attack or other medical problem. It is not possible to be totally sure that a person is having a panic attack. Only a medical professional can tell if it is something more serious. If the person has not had a panic attack before, and doesn't think they are having one now, you should follow physical first aid guidelines. The first step is to help the person into a supported sitting position, e.g. against a wall.

Ask the person, or check to see, if they are wearing a medical alert bracelet or necklace. If they are, follow the instructions on the alert or seek medical assistance.

If the person loses consciousness, apply physical first aid principles. Check for breathing and pulse, and call an ambulance.

What should I say and do if I know the person is having a panic attack?

Reassure the person that they are experiencing a panic attack. It is important that you remain clam and that you do not start to panic yourself. Speak to the person in a reassuring but firm manner, and be patient. Speak clearly and slowly and use short sentences. Invite the person to sit down somewhere comfortable. You could also get them to focus their attention and thinking on something visible like clothes or jewellery they are wearing.[37]

Rather than making assumptions about what the person needs, ask them directly what they think might help.

Do not belittle the person's experience. Acknowledge that the terror feels very real, but reassure them that a panic attack, while very frightening is not life threatening or dangerous. Reassure them that they are safe and that the symptoms will pass.

What should I say and do when the panic attack has ended?

After the panic attack has subsided, ask the person if they know where they can get information about panic attacks. If they don't know, offer some suggestions. Tell the person that if the panic attacks recur, and are causing them distress, they should speak to an appropriate health professional. You should be aware of the range of professional help available for panic attacks in your community. Reassure the person that there are effective treatments available for panic attacks and panic disorder.

Note

It has been widely believed for many years that focussing on breathing during a panic attack can help, either by distracting the person or to bring about a state of calm. Many people still find this to be helpful, and you should not try to stop someone from focussing on their breathing. However, many experts now say that it is not a good idea to actively encourage a person to focus on their breathing, as this can become an emotional crutch, leading to difficult with treatments later on.[153] Instead, simply support the person as described above, and if they feel distressed encourage them to seek professional help.

3.4 First Aid Following a Traumatic Event

Deep Sea

3.4 First Aid Following a Traumatic Event[154]

Facts on traumatic events

A *traumatic event* is any incident experienced by a person that is perceived to be traumatic. Common examples of traumas include accidents, assault (including physical or sexual assault, mugging or robbery, or family violence), and witnessing something terrible happen. Mass traumatic events include terrorist attacks, mass shootings, warfare and military activity, and severe weather events (hurricanes, tsunami and bush fire).

Mental health first aid might not always occur immediately after the traumatic event. For instance, there are other sorts of traumas that are not single discrete incidents. Recurring trauma includes sexual, physical or emotional abuse, torture, and bullying in the schoolyard or workplace, or memories of a traumatic events which suddenly or unexpectedly return, weeks, months or even years afterwards. In the se cases, mental health first aid should be given when the first aider becomes aware of the person's distress.

It is important to know that people can differ a lot in how they react to traumatic events:

- **One person may perceive an event as deeply traumatic, while another does not.**
- **Particular types of traumas may affect some individuals more than others.**
- **A history of trauma may make some people more susceptible to alter traumatic events, while others become more resilient as a result.**

How to assess

A person who has experienced a traumatic event may react strongly right away, showing you that they need immediate assistance. Others may have a delayed reaction. This means that if you are helping someone you know and see on a regular basis, you may be continually assessing them for signs of distress over the next few weeks.

How to assist

What are the first priorities for helping someone after a traumatic event?

If relevant, you need to ensure your own safety before offering help to anyone. Check for potential dangers, such as fire, weapons, debris, or other people who may become aggressive, before deciding to approach a person to offer your help. If you are helping someone who you do not know, introduce yourself and explain what your role is. Find out the person's name and use it when talking to them. Remain calm, and do what you can to create a safe environment, by taking the person to a safer location or removing any immediate dangers.

If the person is injured, it is important that their injuries are attended to. If you are able to, offer the person first aid for their injuries, and seek medical assistance. If the person seems physically unhurt, you need to watch for signs that their physical or mental state is declining, and be prepared to seek emergency medical assistance for them. Be aware that a person may suddenly become disoriented, or an apparently uninjured person may have internal injuries that reveal themselves more slowly.

Try to determine what the person's immediate needs are for food, water, shelter or clothing. However, if there are professional helpers nearby (police, ambulance, or others) who are better able to meet those needs, don't take over their role.

If the person has been a victim of assault, you need to consider the possibility that forensic evidence may need to be collected e.g. evidence on clothing or skin. Work with the person in preserving such evidence, where possible. For example, they may want to change their clothes and shower, which may destroy forensic evidence. It may be helpful to put clothing in a bag for police to take as evidence and suggest to the person that they wait to shower until after a forensic exam. Although collecting evidence is important, you should not force the person to do anything that they don't want to do.

Do not make any promises you may not be able to keep. For example, don't tell someone that you will get them home soon, if this may not be the case.

What are the priorities if I am helping after a mass traumatic event?

Mass traumatic events are those that affect large numbers of people. They include severe environmental events (such as fires and floods), acts of war and terrorism, and mass shootings. In addition to the general principles outlined above, there are a number of things you need to do.
Find out what emergency help is available. If there are professional helpers at the scene, you should follow their directions.

Be aware of and responsive to the comfort and dignity of the person you are helping, for example by offering the person something to cover themselves with (such as a blanket) and asking bystanders or media to go away. Try not to appear rushed or impatient.

Give the person truthful information and admit that you lack information when this is the case. Tell the person about any available sources of information which are offered to survivors (for example, information sessions, fact sheets and phone numbers for information lines) as they become available Do not try to give the person any information they do not want to hear, as this can be traumatic in itself.

How do I talk to someone who has experienced a traumatic event?

When talking to a person who has experienced a traumatic event, it is more important to be genuinely caring than to say all the 'right things'. Show the person that you understand and care, and ask them how they would like to be helped. Speak clearly and avoid clinical and technical language, and communicate with the person as an equal, rather than as a superior or expert. If the person seems unable to understand what is said, you may need to repeat yourself several times. Be aware that providing support doesn't have to complicated; it can involve small things like spending time with the person, having a cup of tea or coffee, chatting about day-to-day life or giving them a hug. However, do not assume that touches or hugs will be reassuring for the person with an intellectual disability who is experiencing PTSD. The initial trauma may have involved physical contact, so ask if it is all right to comfort in this way.

Behaviour such as withdrawal, irritability and bad temper may be a response to the trauma, so try not to take such behaviour personally. Try to be friendly, even if the person is being difficult. The person may not be as distressed about what has happened as you might expect them to be, and this is fine. Don't tell the person how they should be feeling. Tell them that everyone deals with trauma at their own pace. Be aware that cultural differences may influence he way some people respond to a traumatic event; for example, in some cultures, expressing vulnerability or grief around strangers is not considered appropriate.

How can I help the person to cope over the next few weeks or months?

If you are helping someone you know after a traumatic event, you can help them to cope with their reactions over the next few weeks or months. You may be helping a family member, perhaps a spouse, sibling or parent who you are living with or a person with an intellectual disability that you are providing direct support or care to. If you are helping someone you don't know, unless you are responsible for them in some professional capacity, it is not expected that you will have further contact with them.

Encourage the person to tell others when they need or want something, rather than assume others will know what they want. For a person with an intellectual disability you may want to alert their family, friends or carers of the need to keep 'checking in' with them and looking for other signs that the person may need or want something. They may need additional support to engage others due to difficulties initiating this contact. Are there people around who the person feels they can talk to and are familiar with the person's method of communication? Visual methods such as drawings, pictures etc may be required to assist the person to communicate how they are feeling.

Encourage the person to take care of themselves; to get plenty of rest if they feel tired, to do things that feel good to them (e.g. take baths, read, exercise, watch television), and to think about any coping strategies they have successfully used in the past and use them again. Encourage them to spend time somewhere they feel safe and comfortable. You may need to provide support to a person with an intellectual disability in order for them to be able to participate in the above activities.

If you think the person is experiencing a flashback, try and anchor them in the 'here and now' by quietly reminding them where they are and what the current circumstances are. If possible try and remove the triggers from the environment.

When should the person seek professional help?

Not everyone will need professional help to recover from a traumatic event. Research has shown that, in an attempt to prevent PTSD, providing psychological help to everyone within three months following a traumatic event is not helpful and may even have an adverse effect on some individials.[155] However, if the person wants to seek help, you should support them to do so. Be aware of the sorts of professional help that are available locally, and if the person does not like the first professional they speak to, you should tell them that it is okay to try a different one. If the person hasn't indicated that they want professional help, the following guidelines can help you to determine whether help is needed.

If at any time the person becomes suicidal, you should seek professional help. Section 3.1 *First Aid for Suicidal Thoughts and Behaviours* may be useful in helping you to do this. Also, if at any time

the person abuses alcohol or other drugs to deal with the trauma, you should encourage them to seek professional help.

After 4 weeks, some return to normal functioning is expected. You should encourage and support the person to seek professional help if, for 4 weeks or more, after the trauma:

- They still feel very upset or fearful
- They are unable to escape intense, ongoing distressing feelings
- Their important relationships are suffering as a result of the trauma (e.g. if they withdraw from their family or friends)
- They feel jumpy or have nightmares because of or about the trauma
- They can't stop thinking about the trauma
- They are unable to enjoy life at all as a result of the trauma
- Their post-trauma symptoms are interfering with their usual activities.

3.5 First Aid for Severe Psychotic States

Great Cat

3.5 First Aid for Severe Psychotic States[101, 102]

Facts on severe psychotic states

If someone has a psychotic illness, they may at times experience severe psychotic states. Some people experience a severe psychotic state only rarely, perhaps every few years; others more frequently and some may experience these states several times a year.

A severe psychotic state can occur without an apparent cause or may be triggered by something specific. Possible riggers include extra stresses or life events (even positive life events such as a new job or holiday). Forgetting to take medication, or choosing not to, can also trigger a psychotic episode and this is one of the reasons that it is best for people to continue using their medication as prescribed.

A severe psychotic state may develop gradually over a few days or may seem to come on very suddenly. For this reason, early signs of a psychotic state should be addressed as quickly as possible.

How to assess

A person in a severe psychotic state can have;

- Overwhelming delusions and hallucinations
- Very disorganised thinking
- Bizarre and disruptive behaviours.

The person will appear very distressed or their behaviours will be disturbing to others. When a person is in this state, they can come to harm unintentionally because of their delusions or hallucinations e.g. the person believes they have special powers to protect them from danger such as driving through red lights, or the person may run through traffic to try to escape from their terrifying hallucinations.

How to assist

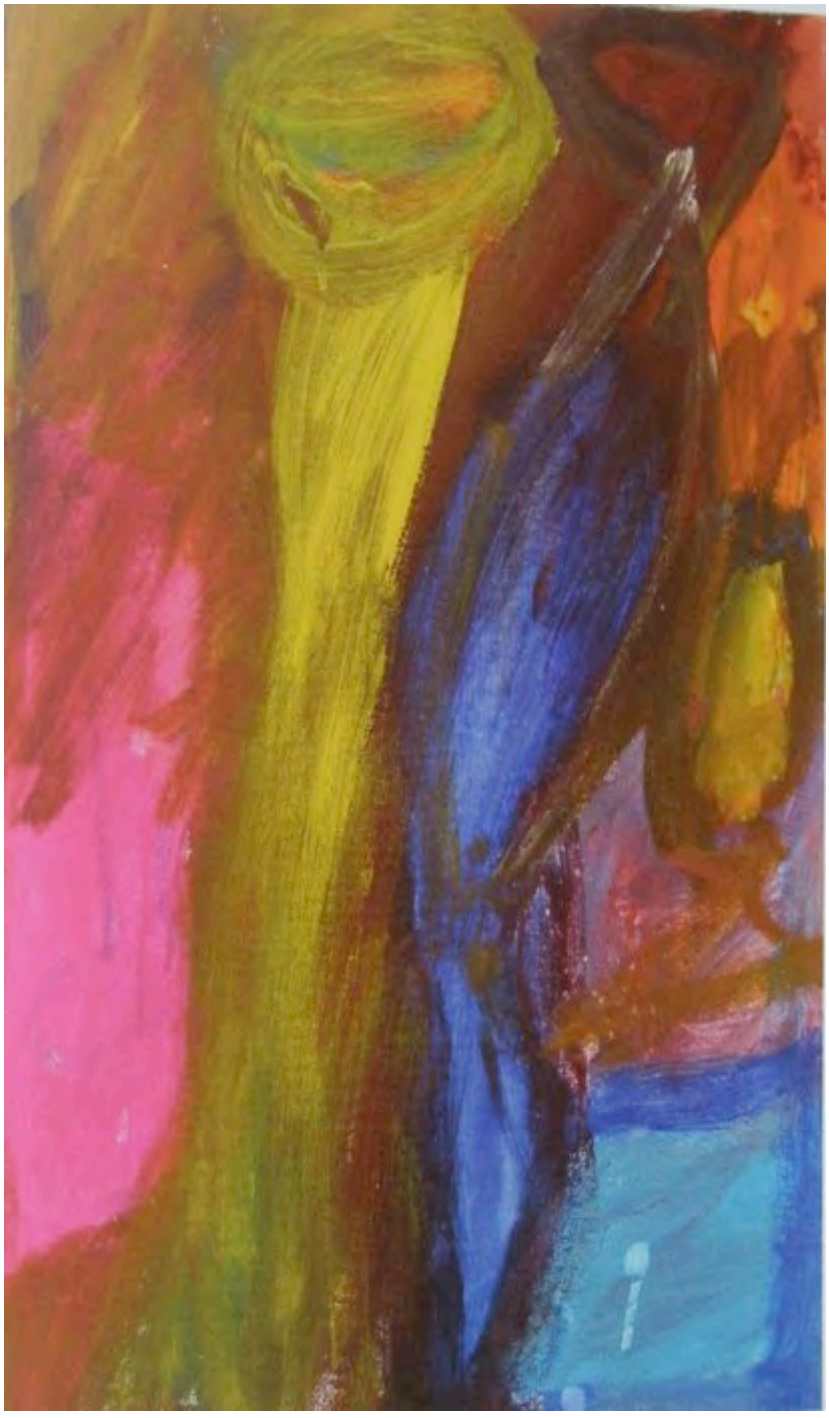
When helping someone in a severe psychotic state, you should try to remain as calm as possible. It is important to communicate to the person in a clear and concise manner and use short, simple sentences. Speak quietly in a non-threatening tone of voice and at a moderate pace. If the person asks you questions, answer them calmly. You should comply with requests unless they are unsafe or unreasonable. This gives the person the opportunity to feel somewhat in control.

If the person has an advance directive or relapse prevention plan, you should follow those instructions. Try to find out if the person has anyone they trust (e.g. close friends, family, support workers) and enlist their help. You should also assess whether it is safe for the person to be alone and, if not, should ensure that someone stays with them.

It is possible that the person might act upon a delusion or hallucination. Remember that your primary task is to de-escalate the situation and therefore you should not do anything to further agitate the person. Try to maintain safety and protect the person, yourself and others around you from harm. It may help to invite the person to sit down. Make sure that you have access to an exit.

Sometimes it is not possible to de-escalate the situation and if this is the case, you should be prepared to call for help form emergency services and convey specific, concise observations about the severity of the person's behaviour and symptoms. When any unfamiliar helpers arrive, explain to the person who they are and how they are going to help. However, if you concerns about the person are dismissed by the services you contact, you should persevere in trying to seek support for them.

3.6 First Aid for Severe Effects from Alcohol Misuse



Bottles

3.6 First Aid for Severe Effects from Alcohol Misuse[133, 134]

Facts on alcohol intoxication, poisoning and withdrawal

Alcohol intoxication **refers to significantly elevated levels of alcohol in a person's blood stream, which substantially impairs the person's thinking and behaviour.**

Alcohol poisoning **means the person has a toxic level of alcohol in the blood stream. This can lead to ther person's death. The amount of alcohol that causes alcohol poisoning is different for every person.**

Alcohol withdrawal **refers to the unpleasant symptoms a person experiences ehn they stop drinking or drink substantially less than usual. Unmedicated alcohol withdrawal may lead to seizures.**

How to assess

Common signs and symptoms of ***alcohol intoxication*** include:

- Loss of coordination
- Slurred speech
- Staggering or falling over
- Loud argumentative or aggressive behaviour
- Vomiting
- Drowsiness or sleepiness.

Signs and symptoms of ***alcohol intoxication and poisoning*** which may lead to a medical emergency are:

- Continuous vomiting
- Vomiting and unconsciousness
- Cannot be woken

  Unconsciousness
- Signs of a possible head injury (for example, vomiting and talking incoherently)
- Irregular, shallow or slow breathing
- Irregular, weak or slow pulse rate
- Cold, clammy, pale or bluish coloured skin.

Signs and symptoms of ***severe alcohol withdrawal*** which may lead to a medical emergency are:

- Delirium tremens (a state of confusion and visual hallucinations)
- Agitation
- Fever
- Seizures

How to assist

If the person is intoxicated:

- ***Stay calm***
- ***Communicate appropriately.*** Talk with the person in a respectful manner and use simple, clear language. Do not laugh at, make fun of, or provoke the person.
- ***Monitor for danger.*** While intoxicated, the person may engage in a wide range of risky activities (such as having unprotected sex, vandalising property or driving a car). Assess the situation for potential dangers and ensure that the person, yourself and others are safe. Monitor the person and their environment to prevent ripping or falling Ask the person if they have taken any medications or other drugs, in case their condition deteriorates into a medical emergency.
- ***Ensure the person's safety.*** Stay with the person or ensure they are not left alone. Be aware that the person may be more intoxicated than they realise. Keep them away from machines and dangerous objects. If the person attempts to drive a vehicle (or ride a bike), you should try to discourage them (for example, by telling them about the risks to both themselves and others). Only prevent the person from driving if it is safe to do so. If it is unsafe, call the police. Arrange for the person to go to a hospital if you think the person is a risk to themselves; otherwise organise a safe mode of transport to get the person home. Alcohol intoxication, poisoning and withdrawal may lead to medical emergencies.

When to call an ambulance

Call an ambulance or seek medical help in any of the following circumstances:

- The person cannot be woken
- The person is unconscious

- The person has irregular, shallow or slow breathing
- The person has an irregular, weak or slow pulse rate
- The person has cold, clammy, pale or bluish coloured skin
- The person is continuously vomiting
- The person shows signs of a possible head injury (for example, they are vomiting and talking incoherently)
- The person has seizures
- The person has delirium tremens – a state of confusion and visual hallucinations.
- Drink spiking is suspected

Tips about calling an ambulance

- Do not be afraid to seek medical help for the person, even if there may be legal implications for the person. Be aware that ambulance officers and hospital staff are there to help the person and not to enforce the law.
- When you call for an ambulance, it is important that you follow the instructions of the telephone operator.
- When asked, describe the person's symptoms and explain that the person has been drinking alcohol.
- If the person is on medication, where possible provide the details of their medication to the medical staff. This information will assist them to give the most appropriate help.
- Have the address of where you are to give to the telephone operator and stay with the person until the ambulance arrives.
- It is beneficial for a friend, family member or support worker to accompany the person to hospital as they may be able to provide relevant information.

What to do while waiting for the ambulance

Be aware that alcohol consumption can mask pain from injuries. Ensure that:

- The person is not left alone. Reassure them that help has been sought and you will stay with them until it arrives
- No food is given to the person as they may choke on it if they are not fully conscious. Explain to the person that it will be safer to eat or drink after a professional has examined them
- The person's airway, breathing and circulation are monitored
- If the person is hard to wake, put them in the recovery position (see *Helping an unconscious person* below)
- If the person is vomiting and conscious, keep the person sitting. Alternatively, put them in the recovery position. If necessary, clear the person's airway after they have vomited.

Can I help the person sober up?

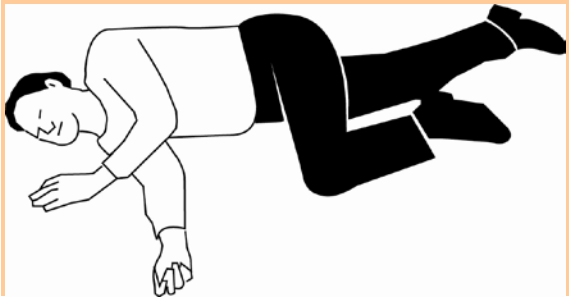
Only time will reverse the effects of intoxication. The body metabolises approximately one standard drink of alcohol an hour. Drinking black coffee, sleeping, walking and cold showers will not speed this process up.

What do I do if the intoxicated person becomes aggressive?

If this occurs, follow the advice in Section 3.8 *First Aid for Aggressive Behaviours.*

Helping an unconscious person

Do not leave the person lying on their back as they could suffocate on their vomit or their tongue could block their airways. Putting the person in the recovery position will help to keep the airway open. Before rolling the person into the recovery position, check for sharp objects (e.g. broken glass or syringes on the ground). If necessary, clear the person's airway after they have vomited. Keep the person warm without allowing them to overheat.



3.7 First Aid for the Severe Effects of Drug Misuse

Twin Game

3.7 First Aid for the Severe Effects from Drug Misuse[135]

Facts on drug-affected states

Drug-affected states are short-term changes in a person's state of mind or behaviour as a result of drug use. These states distress the person or impair their ability to function. The effects of drugs on behaviour can vary from person to person depending on the sort of drug that has been used and the amount that is taken. Illicit drugs can have carrying effects, as they are not manufactured in a controlled way. It is often difficult to make a distinction between the effects of different drugs. *Overdose* refers to use of an amount of a drug which could cause death, most typically opioid drugs. Overdose leads quickly to a loss of consciousness.

How to assess

Some drugs have **stimulating effects** ('uppers' such as cocaine and amphetamines) including making the person feel energetic and confident. Signs of more acute intoxication include becoming frustrated or angry, having a racing hear, and overheating or dehydration.

Some drugs have **hallucinogenic effects** ('trips' such as magic mushrooms and LSD), including hallucinations and delusions and feelings of affection for others. Signs of more acute intoxication include having more negative hallucinations and delusions and becoming fearful or paranoid.

Some drugs have **depressant effects** ('downers' such as cannabis and tranquilisers) including fatigue, slurred speech and slowed reflexes. Signs of more acute intoxication include feelings of having trouble moving, vomiting and loss of consciousness. Some drugs (such as ecstasy and cannabis) may have multiple effects. This is why I can be hard to tell what sort of drug has been used.

Overheating or dehydration from drug misuse can also lead to a medical emergency. Prolonged dancing in a hot environment (such as a dance party) while on some drugs (e.g. ecstasy) without adequate water intake, can cause the person's body temperature to rise to dangerous levels. This can lead to symptoms of overheating or dehydration, such as:

- Feeling hot, exhausted and weak
- Persistent headache
- Pale, cool, clammy skin
- Rapid breathing and shortness of breath
- Fatigue, thirst and nausea
- Giddiness and feeling faint.

How to assist

If the person is in a drug-affected state:

- ***Stay calm***
- ***Communicate appropriately.*** Talk with the person in a respectful manner and use simple, clear language. Be prepared to repeat simple requests and instructions as the person may find it difficult to comprehend what has been said. Do not speak in an angry manner. Do not laugh at, make fun of, or provoke the person.
- ***Monitor for danger.*** While in a drug-affected state the person may engage in a wide range of risky activities (such as having unprotected sex, vandalising property or driving a car). Assess the situation for potential dangers and ensure that the person, yourself and others are safe. Monitor the person and their environment to prevent ripping or falling
- ***Ensure the person's safety.*** Stay with the person or ensure they are not left alone. Be aware that the person may be more affected than they realise. Keep them away from machines and dangerous objects. If the person attempts to drive a vehicle (or ride a bike), you should try to discourage them (for example, by telling them about the risks to both themselves and others). Only prevent the person from driving if it is safe to do so. If it is unsafe, call the police. Arrange for the person to go to a hospital if you think the person is a risk to themselves; otherwise organise a safe mode of transport to get the person home. Encourage the person to tell someone if they start to feel unwell or uneasy, and to call emergency services if they have an adverse reaction. Drug use can lead to medical emergencies.

When to call an ambulance

Call an ambulance or seek medical help in any of the following circumstances:

- The person cannot be woken
- Deteriorating or loss of consciousness

- The person has irregular, shallow or slow breathing
- The person has an irregular, weak or slow pulse rate
- The person has cold, clammy, pale or bluish coloured skin
- The person is continuously vomiting
- The person shows signs of a possible head injury (for example, they are vomiting and talking incoherently)
- The person has seizures
- The person has delirium– a state of confusion and visual hallucinations.
- Overheating, dehydration and overhydration

Tips about calling an ambulance

- Do not be afraid to seek medical help for the person, even if there may be legal implications for the person. Be aware that ambulance officers and hospital staff are there to help the person and not to enforce the law.

- When you call for an ambulance, it is important that you follow the instructions of the telephone operator.

- When asked, describe the person's symptoms and explain that the person has been using drugs. Try to get detailed information about what drugs the person has taken by either asking the person, their friends or visually scanning the environment for clues.

- If the person is on medication, where possible provide the details of their medication to the medical staff. This information will assist them to give the most appropriate help.

- Have the address of where you are to give to the telephone operator and stay with the person until the ambulance arrives.

- It is beneficial for a friend, family member or support worker to accompany the person to hospital as they may be able to provide relevant information.

What to do while waiting for the ambulance
Ensure that:

- The person is not left alone. Reassure them that help has been sought and you will stay with them until it arrives

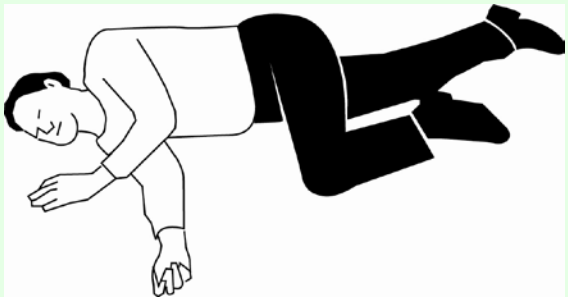
- No food is given to the person as they may choke on it if they are not fully conscious. Explain to the person that it will be safer to eat or drink after a professional has examined them

- The person's airway, breathing and circulation are monitored
- If the person is hard to wake, put them in the recovery position (see *Helping an unconscious person* below)

- Give first aid for any overheating or dehydration (see *Helping a person who is overheating or dehydrated* below).

Helping an unconscious person

Do not leave the person lying on their back as they could suffocate on their vomit or their tongue could block their airways. Putting the person in the recovery position will help to keep the airway open. Before rolling the person into the recovery position, check for sharp objects (e.g. broken glass or syringes on the ground). If necessary, clear the person's airway after they have vomited. Keep the person warm without allowing them to overheat.



Helping a person who is overheating or dehydrated

If the person is showing symptoms of overheating or dehydration, you must keep the person calm and seel medical help immediately. Encourage the person to stop dancing and to rest somewhere quiet and cool. While waiting for help to arrive, reduce the person's body temperature gradually. Do this by loosening any restrictive clothing or removing any additional layers, and encourage the person to sip non-alcoholic fluids, e.g. water and soft drinks. Prevent the person form drinking too much water at once as this may lead to overhydration and even coma or death. Discourage the person from drinking alcohol as it may further dehydrate them.

What do I do if the intoxicated person becomes aggressive?

If this occurs, follow the advice in Section 3.8 *First Aid for Aggressive Behaviours.*

3.8 First Aid for Aggressive Behaviours

Bushfire

3.8 First Aid for Aggressive Behaviours[102, 134]

Facts on aggressive behaviours

The vast majority of people with mental illnesses are not dangerous to others. Only a small proportion (up to 10%0 of violence in society is due to mental illness.[94,95,96] Depression and anxiety disorders have little or no association with violent behaviour towards others. However, there is an increased risk of violence for people who experience substance use disorders, personality disorders or psychois.[97] The use of alcohol or other drugs has a stronger association with violence that do mental illnesses. Many crimes are committed by people who are intoxicated with alcohol or other drugs.

How to assess

Aggression has different components to it – verbal (e.g. insults or threats), behavioural (pounding, throwing things, violating personal space) and emotional (e.g. raised voice, looks angry). What is perceived as aggression can vary between individuals and across cultures. It is best to prevent aggression and therefore take de-escalation action as soon as you perceive it. If you are concerned that the person is becoming aggressive, you need to take steps to protect yourself and others.

How to assist

If the person becomes aggressive, ensure your own safety at all times. Remain as calm as possible and try to create a calm, non-threatening environment when attempting to de-escalate the situation. At all times you should try to ensure the privacy, dignity and respect of the person you are trying to assist. For a person with an intellectual disability there may already be a crisis plan in place, check if this is the case. If not one should be developed as soon as possible.

How to de-escalate the situation[68]

- Speak to the person slowly, clearly and confidently with a gentle, caring tone of voice.
- Be firm but avoid raising your voice or talking too fast.
- Listen carefully to what the person says.
- Do not respond in a hostile, disciplinary or challenging manner. This includes both verbal and body language.
- Do not argue with the person.
- Ask them to explain what has upset them.
- Give the person time to respond.
- Acknowledge what the person has said but do not agree or disagree with them. E.g. do not pretend that you can see or hear the hallucinations or delusions. Do not try to reason with them about their delusions and hallucinations.
- Consider taking a break from the conversation to allow the person a chance to calm down.
- Reassure them if they are worried.
- Do not make promises that cannot be kept.
- Comply with reasonable requests. This will provide the person with a feeling that they are somewhat 'in control'.
- Be non-judgemental and avoid using threatening language. Be aware that the person may overreact to negative or critical words; therefore, use positive words (such as "stay calm") instead of negative words (such as "don't fight").
- Stay calm and avoid nervous behaviour (e.g. shuffling your feet, fidgeting, making abrupt movements).
- Adopt a neutral stance and keep your hands at your side, avoid folding your arms or pointing and do not stand directly in front of the person.
- Do not restrict the person's movement or try to restrain them unless in self defence, (e.g. if he or she wants to pace up and down the room).
- Do not threaten them as this may increase fear or prompt aggressive behaviour.
- Remain aware that the person's symptoms or fear causing their aggression might be exacerbated if you take certain steps (e.g. involve the police).
- Make eye contact (but remember some people, such as those with autism, may find this threatening). Keep eye contact natural, glance away occasionally to avoid staring.

- Stay at the same level as the person – if they are sitting, you should sit, if they are standing you should stand. Consider inviting the person to sit down if they are standing.

Take any threats or warnings seriously, particularly if the person believes they are being persecuted. If you are frightened, seek outside help immediately. You should never put yourself at risk, always ensure you have access to an exit and are aware of potential hazards in the environment. Consider whether the environment can be altered to prevent the situation escalating. If the person's aggression escalates out of control at any time, you should remove yourself from the situation and call for emergency assistance (e.g. the mental health crisis team or the police). If working with a person with an intellectual disability you could contact the on-call manager if this is part of the protocol before calling the police or mental health crisis team. When you call the police tell them that the person has a mental illness and an intellectual disability and may require medical help. Ask if possible that they send a plain-clothes police officer so the person will feel less threatened.

You may also need to think about the safety of others where the person is volatile particularly if you are supporting a person with an intellectual disability living or working in a group situation;
Make sure others are aware of the situation. Ask other staff members to support other people present and keep the area clear of other clients and distractions while you help the person.

If you believe that the aggression is related to a mental health problem, you may need to call the **mental health crisis team**. If you do so, it is best to describe the person's symptoms and behaviours rather than trying to make a diagnosis of your own. Let the team know that the person also has an intellectual disability. Be aware that the crisis team may not attend without a police presence.

If the situation becomes unsafe, it may be necessary to involve the **police**. If you suspect that the person's aggression is related to the mental health problem, to assist the police in their response, you should tell them that this is the case and that you need their help to obtain medical treatment and to control the person's aggressive behaviour.

Aggressive behaviour is frequently associated with intoxication with alcohol or another drug. If this is the case, and you decide to call the police, tell the police that you believe the person is intoxicated, and what substances you believe have been used.

In either case, you should tell the police whether or not the person is armed.

References

References

1. World Health Organization. *Mental Health Strengthening Mental Health Promotion (Fact Sheet No 220).* Geneva: WHO; 2007

2. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR).* Washington DC: American Psychiatric Association; (2000)

3. Australian Bureau of Statistics. *2007 National Survey of Mental Health and Wellbeing: Summary of Results. (Document 4326.0).* Canberra: ABS; 2008

4. Australian Institute of Health and Welfare. *Measuring the Social and Emotional Wellbeing of Aboriginal and Torres Strait Islander Peoples. (Cat. No. IHW 24)*. Canberra: AIHW; 2009

5. Jablensky A, McGrath J, Herrman H, Castle D, Gureje O, Morgan V, Korten A. *People Living with Psychotic Illness: An Australian study 1997-98 An overview.* Canberra: Commonwealth Department of Health and Aged Care; 1999

6. Slade T, Johnston A, Oakley Browne MA, Andrews G, Whiteford H. 2007 National Survey of Mental Health and Wellbeing: methods and key findings. *Australian & New Zealand Journal of Psychiatry* 2009; 43: 594-605

7. Marshall M, Lewis S, Lockwood A, Drake R, Jones P, Croudace T. Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review. *Archives of General Psychiatry* 2005; 62: 975-83

8. Dosen A, Day K. Epidemiology, etiology and presentation of mental illness and behaviour disorders in persons with mental retardation. In: Dosen A, Day K, editors. *Treating mental illness and behaviour disorders in children and adults with mental retardation.* Washington: American Psychiatric Press. 2001

9. Tonge BJ, Einfeld SL, Glidden LM. (2003). Psychopathology and intellectual disability: The Australian child to adult longitudinal study International review of research in mental retardation, Vol. 26.: Academic Press, 61-91

10. Holt G, Hardy S, Bouras N *Mental Health in Learning Disabilities. A Reader.* Brighton, UK. Pavilion Publishing. 2008

11. Australian Institute of Health and Welfare. *Disability in Australia: Intellectual Disability*. (Bulletin 67). Canberra: AIHW 2008

12. Hughes E. Technical Assistance Manual/Clinical Issues. Chapter Six: Dual Diagnosis. 2000

13. Cooray S E, Bakala A. Anxiety disorders in people with learning disabilities. *Advances in Psychiatric Treatment* 2005; 11: 355-61

14. Deb S, Matthews T, Holt G, Bouras N. Practice Guidelines for the Assessment and Diagnosis of Mental Health Problems in Adults with Intellectual disability. Pavillion, Brighton. 2000

15. Unpublished data from the *2007 National Survey of Mental Health and Wellbeing*

16. Stouthard MEA, Essink-Bot ML, Bonsel GJ, Barendregt JJ, Kramer PG, Water HPA, Gunning-Schepers LJ, van der Maas PJ, *Disability Weights for Diseases in the Netherlands.* Rotterdam: Erasmus University; 1997

17. Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez AD. *The Burden of Disease and Injury in Australia in 2003.* Canberra: Australian Institute of Health and Welfare; 2007

18. World Health Organization. *Diagnostic and Management Guidelines for Mental Disorders in Primary Care: ICD-10 Chapter V Primary Care Version.* Geneva: WHO; 1996

19. Hardy S., Chaplin E., Mental health nursing of adults with learning disabilities. RCN guidance. [Electronic Resource] London UK; Royal College of Nursing

20. Unit 2 Mental Health of Adults with an Intellectual Disability. Module 2:1 Mental Health Problems & Disorders. QLD training package

21. Disability SA Information Sheet, Dual Disability. What does it mean? 2006

22. Hardy S, Kramer R, Holt G, Chaplin E, Janjua A (Ed). (no date) Supporting Complex needs. A practical guide for support staff working with people with a learning disability who have mental health needs. Estia Centre UK

23. Bouras N, Holt G, Day K, Dosen A (eds). (2000) Mental Health in Mental Retardation: The ABC for mental health, primary care & other professionals. (2nd ed)

24. Cusack J, Deane FP, Wilson CJ, Ciarrochi J. Who influences men to go to therapy? Reports from men attending psychological services. *International Journal for the Advancement of Counselling* 2004; 26: 271-83

25. Dew MA, Bromet EJ, Schulberg HC, Parkinson DK, Curtis EC. Factors affecting service utilization for depression in a white collar population. *Social Psychiatry and Psychiatric Epidemiology* 1991; 26: 230-7

26. Neilson A, White P. Non-Pharmacological Interventions Unit 5 Mental Health of Adults with an Intellectual Disability. QLD training package

27. Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal* 1993: 16: 11-23

28. Copeland ME. *Mental Health Recovery Including Wellness Recovery Action Planning Program Description*.[Online]. Available from: http://www.mentalhealthrecovery.com/art_wrap.php

29. Deegan PE. Recovery: the lived experience of rehabilitation. *Psychosocial Rehabilitation Journal* 1998; 11: 11-9

30. Hocking B. Reducing mental illness stigma and discrimination – everybody's business. *Medical Journal of Australia* 2003; 178: S47-8

31. Jorm AF, Kelly CM. Improving the public's understanding and response to mental disorders. *Australian psychologist* 2007; 42: 81-9

32. Barney LJ, Griffiths KM, Jorm AF, Christensen H. Stigma about depression and its impact on help-seeking intentions. *Australian & New Zealand Journal of Psychiatry* 2006; 40: 51-4

33. Kitchener BA, Jorm AF. Mental health first aid training for the public: evaluation of effects on knowledge, attitudes and helping behaviour. *BMC Psychiatry* 2002: 2:10

34. Kitchener BA, Jorm AF. Mental health first aid training in a workplace setting: a randomized controlled trial [ISRCTN13249129]. *BMC Psychiatry* 2004; 4: 23

35. Jorm AF, Kitchener BA, O'Kearney R, Dear KBG. Mental heath first aid training of the public in a rural area; a cluster randomized trial [ISRCTN53887541]. *BMC Psychiatry* 2004; 4: 33

36. Jorm AF, Kitchener BA, Mugford SK. Experiences in applying skills learned in a mental health first aid training course: a qualitative study of participants' stories. *BMC Psychiatry* 2005; 5: 43

37. Nugent J. (2005) A Handbook on Dual Diagnosis 3rd Edition. Supporting people with a developmental disability and a mental health problem. Nugent training & Consulting Services. Mississauga

38. Huggins JE, Grant T, O'Malley K, Streissguth AP. Suicide attempts among adults with fetal alcohol spectrum disorders: Clinical considerations. *Mental Health Aspects of Developmental Disabilities.* 2008; 11: 33-41

39. Teesson M, Slade T, Mills K. Comorbidity in Australia; findings of the 2007 National Survey of Mental Health and Wellbeing. *Australia & New Zealand Journal of Psychiatry* 2009; 43: 606-14

40. Smiley E. Epidemiology of mental health problems in adults with learning disability: an update. *Advances in Psychiatric Treatment*. 2005;11: pp 214-222

41. Post RM. Transduction of psychosocial stress into the neurobiology of recurrent affective disorder. *American Journal of Psychiatry* 1992; 149: 999-1010

42. Byrne C, Hurley AD., James R. Planning Guidelines for Mental Health and Addiction Services for Children, Youth, and Adults with Developmental Disability. British Columbia Ministry of Health. BC; 2007

43. Canuso CM, Bossie CA, Zhu Y, Youssef E, Dunner DL. Psychotic symptoms in patients with bipolar mania. *Journal of Affective Disorders* 2008; 111: 164-9

44. Forty L, Smith D, Jones L, Jones I, Caesar S, Cooper C, et al. Clinical differences between bipolar and unipolar depression. *British Journal of Psychiatry* 2008; 192: 388-9

45. Joyce PR. Epidemiology of mood disorders. In: Gelder MG, Lopez-Ibor JJ, Andreasen N, editors. *New Oxford Textbook of Psychiatry*. Oxford. Oxford University Press; 2000. p.695-701

46. Sourey D, Blairy S, Mendlewicz J. Genetic and social aetiology of mood disorders. In Gelder MG, Lopez-Ibor JJ, Andreasen N. editors. *New Oxford Textbook of Psychiatry*. Oxford: Oxford University Press; 2000. p.701-11

47. Schultz R, Sherwood PR. Physical and mental health effects of family caregiving. *American Journal of Nursing 2008; 108: 23-7*

48. Pooblan AS, Aucott LS, Ross L, Smith WC. Effects of treating postnatal depression on mother infant interaction and child development: systematic review. *British Journal of Psychiatry* 2007; 191: 378-86

49. Buist AE, Austin M-PV, Hayes BA, Speelman C, Bilszta JLC, Gemmill AW, et al. Postnatal mental health of women giving birth in Australia 2002-2004; findings from the beyondblue national Postnatal Depression Program. *Australian & New Zealand Journal of Psychiatry* 2008; 42: 66-73

50. Jorm AF, Allen NB, Morgan AJ, Purcell R. *A Guide to What Works for Depression.* Melbourne: beyondblue; 2009

51. Cooke LB, Thompson C. Seasonal affective disorder and response to light in two patients with learning disability. *Journal of Affective Disorders* 1998; 48: 145-48

52. Parker G, Crawford J. Judged effectiveness of differing antidepressant strategies by those with clinical depression. *Australian & New Zealand Journal of Psychiatry* 2007; 41: 32-7

53. Altamura AC, Dell'Osso B, Vismara S, Mundo E. May duration of untreated illness influence the long-term course of major depressive disorder? *European psychiatry* 2008; 23: 92-6

54. Johnston AK, Pirkis JE, Burgess PM. Suicidal thoughts and behaviours among Australian adults: findings from the 2007 National Survey of Mental Health and Wellbeing. *Australian & New Zealand Journal of Psychiatry* 2009; 43: 635-43

55. Klonsky ED, Muehlenkamp JJ. Self-injury: a research review for the practitioner. *Journal of clinical Psychology* 2007; 63: 1045-56

56. Langlands RL, Jorm AF, Kelly CM, Kitchener BA, First aid for depression: a Delphi consensus study with consumers, carers and clinicians. *Journal of Affective Disorders* 2008; 105: 157-65

57. Mental Health First Aid Training and Research Program. *Depression: First Aid Guidelines.* Melbourne: Orygen Research Centre, University of Melbourne; 2008. Available from; http://www.mhfa.com.au/Guidelines.shtml

58. Scottish Executive NHS. *Scotland's Mental Health First Aid manual.* Edinburgh: NHS Health Scotland; 2005

59. Thompson A, Issakidis C, Hunt C. Delay to seek treatment for anxiety and mood disorders in an Australian clinical sample. *Behaviour Change* 2008: 25: 71-84

60. Bowers J, Jorm AF, Henderson S, Harris P. General practitioner's detection of depression and dementia in elderly patients. *Medical Journal of Australia* 1990; 153: 192-6

61. Herrán A, Vázquez-Barquero JL, Dunn G. Recognition of depression and anxiety in primary care: patients' attributional style is important factor. *British Medical journal* 1999; 318: 1558.

62. Pistrang N, Barker C, Humphreys K. Mutual help groups for mental health problems: a review of effectiveness studies. *American Journal of Community psychology* 2008; 42: 110-21

63. Keitner GI, Ryan CE, Miller IW, Kohn R, Bishop DS, Epstein NB. Role of the family in recovery and major depression. *American Journal of Psychiatry* 1995; 152: 1002-8

64. Weiner A, Wessely S, Lewis G. "You don't give me flowers anymore": an analysis of gift-giving to medical and psychiatric inpatients. *Social psychiatry and Psychiatric Epidemiology* 199; 34: 136-40

65. Jorm AF, Griffiths KM, Christensen H, Parslow RA, Rogers B. Actions taken to cope with depression at different levels of severity: a community survey. *Psychological Medicine* 2004; 34: 293-9

66. Christensen H, Griffiths KM, Jorm AF. Delivering interventions for depression by using the internet: randomised controlled trial. *British Medical Journal* 2004; 328: 265

67. Jamison C, Scogin F. The outcome of cognitive bibliotherapy with depressed adults. *Journal of Consulting and Clinical Psychology* 1995; 63: 644-50

68. McCarthy J. Post-traumatic stress disorder in people with learning disabilities. *Advances in Psychiatric treatment*. 2001; 7: p163-69

69. Jorm AF, Christensen H, Griffiths KM, Parslow RA, Rodgers B, Blewitt KA. Effectiveness of complementary and self-help treatments for anxiety disorders. *Medical Journal of Australia* 2004; 181: S29-46

70. Canadian Psychiatric Association. Clinical practice guidelines: management of anxiety disorders: 2. *Canadian Journal of Psychiatry* 2006; 51: 1S-92S

71. Woodward LJ, Fergusson DM. Life course outcomes of young people with anxiety disorders in adolescence. *Journal of the American Academy of Child & Adolescent Psychiatry* 2001; 40: 1086-93

72. Reavley NJ, Allen NB, Jorm AF, Morgan AJ, Purcell R. *A Guide to What Works for Anxiety Disorders* Melbourne: beyondblue; 2010-06-17

73. Kessler RC, Chiu WT, Jin R, Ruscio AM, Shear K, Walters EE. The epidemiology of panic attacks, panic disorder, and agoraphobia in the National Comorbidity Survey Replication. *Archives of General Psychiatry* 2006; 63: 415-24

74. Arsenault-Lapierre G, Kim C, Turecki G. Psychiatric diagnosis in 3275 suicides; a meta-analysis. *BMC Psychiatry* 2004; 4: 37

75. Gosh A, Marks IM, Carr AC. Therapist contact and outcome of self-exposure treatment for phobias. A controlled study. *British Journal of Psychiatry* 2007; 191: 246-52

76. Rapee RM, Abbott MJ, Baille AJ, Gaston JE. Treatment of social phobia through pure self-help and therapist augmented self-help. *British Journal of Psychiatry* 2007; 191: 246-52

77. International Early Psychosis Association Writing Group. International clinical practice guidelines for early psychosis. *British Journal of Psychiatry* 2005; 187: S120-4

78. Edwards J, McGorry PD. *Implementing Early Intervention in Psychosis: A Guide to Establishing Early psychosis Services.* London: Martin Dunitz; 2002

79. Hart LM, Jorm AF, Kanowski LG, Kelly CM, Langlands RL. Mental health first aid for Indigenous Australians: using Delphi consensus studies to develop guidelines for culturally appropriate responses to mental health problems. *BMC Psychiatry* 2009; 9: 47

80. Saha S, Chant D, Welham J, McGrath J. A systematic review of the prevalence of schizophrenia. *PLoS Medicine* 2005; 2: e141

81. Hafner H. Onset and course of the first schizophrenic episode. *Kaohsiung Journal of Medical Sciences* 1998; 14: 413-31

82. McGrath J, Saha S, Welham J, El Saadi O, McCauley C, Chant D. A systematic review of the incidence of schizophrenia: the distribution of rates and the influence of sex, urbanicity, migrant status and methodology. *BMC Medicine* 2004; 2: 13.

83. Jablensky A. epidemiology of schizophrenia. In: Gender MG, Lopez-Ibor JJ, Andreasen N, editors. *New Oxford Textbook of Pyshicatry.* Oxford: Oxford University Press; 2000. p. 585-99

84. Müller-Oerlinghausen B, Berghöfer A, Bauer M. Bipolar disorder. *Lancet* 2002; 359: 241-7

85. The Royal Collage of Psychiatrists. (2001) *Depression in people with learning disabilities*. Retrieved January 20, 2007, from http://www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthproblems/depression/learningdisability.aspx

86. Tandon R, Keshavan MS, Nasrallah HA. Schizophrenia, "just the fact": what we know in 2008. 2. epidemiology and etiology. *Schizophrenia Research* 2008; 102: 1-18

87. Arseneault L, Cannon M, Witton J, Murray RM. Causal association between cannabis and psychosis: examination of the evidence. *British Journal of Psychiatry.* 2004; 184: 110-7

88. Di Forti M, Lappin JM, Murray RM. Risk factors for schizophrenia-all roads lead to dopamine. *European Neurophshcopharmacology* 2007; 17: 101-7

89. Tsuchiya KJ, Byrne M, Mortensen PR. Risk factors in relation to an emergence of bipolar disorder: a systematic review. *Bipolar Disorders* 2003; 5: 231-42

90. Smoller JW, Finn CT. Family, twin and adoption studies of bipolar disorder. *American Journal of Medical Genetics 2003; 123: 48-58*

91. Tandon R, Keshavan MS, Nasrallah HA. Schizophrenia, "just the facts": what we know in 2008 part 1; overview. *Schizophrenia Research* 2008; 100: 4-19

92. McGorry P, Killackey E, Elkins K, Lambert M, Lambert T. Summary Australian and New Zealand clinical practice guideline for the treatment of schizophrenia. *Australian & New Zealand psychiatry* 2003; 11: 136-47

93. Yatham LN, Kennedy SH, O'Donovan C, Parikh S, MacQueen G, McIntyre R, et al. Canadian Network for Mood and Anxiety Treatments (CANMAT) guidelines for the management of patients with bipolar disorder: consensus and controversies. *Bipolar Disorders* 2005; 7: S5-69

94. Wallace C, Mullenn P, Burgess P, Palmer S, Ruschena D, Browne C. Serious criminal offending and mental disorder. case linkage study. *British Journal of Psychiatry* 1998; 172: 477-84

95. Noffsinger SG, Resnick PJ. Violence and mental illness. *Current opinion in Psychiatry* 1999; 12: 683-7

96. Walsh E, Buchanan A, Fahy T. violence and schizophrenia; examining the evidence. *British Journal of Psychiatry* 2002; 180: 490-5

97. Arseneault L, Moffitt TE, Caspi A, Taylor PJ, Silva PA. Mental disorders and violence in a total birth cohort: results from the Dunedin study. *Archives of General psychiatry* 2000; 57: 979-86

98. Palmer BA, Pankratz VS, Bostwick JM. The lifetime risk of suicide in schizophrenia: a re-examination. *Archives of General psychiatry* 2005; 62: 247-53

99. Simpson SG, Jamison KR. The risk of suicide in patients with bipolar disorders. *Journal of Clinical Psychiatry* 1999; 60: 53-6

100. Hawton K, Sutton L, Haw C, Sinclair J, Deeks JJ. Schizophrenia and suicide: systematic review of risk factors. *British Journal of Psychiatry* 2005; 187: 9

101. Langlands RL, Jorm AF, Kelly CM, Kitchener BA. First aid recommendations for psychosis: using the Delphi method to gain consensus between mental health consumers, carers, and clinicians. *Schizophrenia Bulletin* 2008; 34: 435-443

102. Mental Health First Aid Training and Research Program. *Psychosis: First Aid Guidelines.* Melbourne: ORYGEN Research Centre, University of Melbourne; 2008. Available from: http://www.mhfa.com.au/Guidelines. shtml

103. Pharoah FM, Rathbone J, Mari JJ, Streiner D. Family intervention for schizophrenia. *Cochrane Database of Systemic Reviews* 2003; 3: CD000088

104. Phillips P, Johnson S. How does drug and alcohol misuse develop among people with psychotic illness? A literature review. *Social Psychiatry and Psychiatric Epidemiology* 2001; 36: 269-76

105. Linszen DH, Dingemans MP, Lenior ME. Cannabis abuse and the course of recent-onset schizophrenic disorders. *Archives of General Psychiatry* 1994; 51: 273-9

106. Commonwealth of Australia Special Gazette. *Therapeutic Goods (listing) Notice 19 July 2001 (no.4)* Department of Health and Ageing. Therapeutic Goods Administration. Available from: http://www.tga.gov.au/legis/tgnlist0104.htm

107. Gregg L, Barrowclough C, haddock G. Reasons for increased substance use in psychosis. *Clinical Psychology Review* 2007; 27: 494-510

108. Bachman SS, Drainoni M-L, Tobias C. Substance Abuse Treatment Services for People with Disabilities: Does Managed Care Prompt Innovation? *Journal of Disability Policy Studies.* 2003;14:154-62.

109. Burgard JF, Donohue B, Azrin NH, Teichner G. Prevalence and treatment of substance abuse in the mentally retarded population: An empirical review. *Journal of Psychoactive Drugs*. 2000; 32:293-98.

110. McCrystal P, Percy A, Higgins K. Substance Use Behaviours of Young People with a Moderate Learning Disability: A Longitudinal Analysis. *American Journal of Drug and Alcohol Abuse*. 2007; 33:155-61.

111. Taggart L, McLaughlin D, Quinn B, Milligan V. An exploration of substance misuse in people with intellectual disabilities. *Journal of Intellectual Disability Research*. 2006; 50: 588-97.

112. Degenhardt L. Interventions for people with alcohol use disorders and an intellectual disability: A review of the literature. *Journal of Intellectual and Developmental Disability*. 2000; 25:135-46.

113. Smith AHW, O'Brien G. Offenders with dual diagnosis. (2004) In: Lindsay WR, Taylor JL, Sturmey P, eds. Offenders with developmental disabilities. West Sussex: Wiley and Sons.

114. National Health and Medical Research Council. *Australian Guidelines to Reduce Health Risks from Drinking Alcohol.* Canberra: National Health and Medical Research Council; 2009

115. Yung A, Cosgrove E. Cigarettes and alcohol: youth at risk. *Australian Doctor* 2006; 10 March: 27-34

116. Yucel M, Solowij N, Respondek C, Whittle S, Fornito A, Pantelis C, et al. Regional brain abnormalities associated with long-term heavy cannabis use. *Archives of General psychiatry* 2008; 65: 694-701

117. Australian Institute of Health and Welfare. *2007 National Drug Strategy Household Survey: Detailed Findings.* Canberra: Australian Institute of Health and Welfare; 2008

118. Handen BL, Gilchrist R. Practitioner Review: Psychopharmacology in children and adolescents with mental retardation. *Journal of Child Psychology and Psychiatry* 2006; 47: 871-82

119. de Win MM, Jager G, Booij, Reneman L, Schilt T, Lavini C, et al. Neurotoxic effects of ecstasy on the thalamus. *British Journal of Psychiatry* 2008; 193: 289-96

120. Parrott AC Recreational ecstasy/MDMA, the serotonin syndrome, and serotonergic neurotoxicity. *Pharmacology, Biochemistry and Behavior*, 2002;71: 837-44

121. McGillivray JA, Moore MR. Substance use by offenders with mild intellectual disability. *Journal of Intellectual and Developmental Disability.* 2001; 26: 297-310

122. de Leon J, Diaz FJ. A meta-analysis of worldwide studies demonstrates an association between schizophrenia and tobacco smoking behaviours. *Schizophrenia research* 2005; 76: 135-57

123. Whitaker S., Hughes M. Prevalence and influences on smoking in people with learning disabilities. *The British Journal of Developmental Disabilities*. 2003; 49: (2), p 91-7

124. Taylor, NS; Standen, PJ; Cutajar, P; Fox, D; Wilson, DN. Smoking Prevalence and prevalence of associated risks in adult attenders at day centres for people with learning disabilities. *Journal of Intellectual Disability Research.* 2004; 48: 3. p 239-44

125. Negrete JC. Aetiology of alcohol problems. In: Gelder MG, Lopez-Ibor JJ, Andreasen N. editors *New Oxford Textbook of Psychiatry*. Oxford: Oxford University Press: 2000 p. 477-82

126. Taggart L, McLaughlin D, Quinn B, McFarlane. Listening to people with intellectual disabilities who misuse alcohol and drugs. *Health & Social Care in the Community*. 2007; 15: 4, 360-68

127. Ary DV, Tildesley E, Hops H, Andrews J. The influence of parent, sibling, and peer modelling and attitudes on adolescent use of alcohol. *Substance use & Misuse* 1993; 28: 853-80

128. Komro KA, Maldonado-Molina MM, Tobler AL, Bonds JR, Muller KE. Effects of home access and availability of alcohol on young adolescents' alcohol use. *Addiction* 2007; 102: 1597-608

129. Westermeyer J, Kemp K, Nugent S. Substance disorder among persons with mild mental retardation: A comparative study. *The American Journal on Addictions*. 1996; 5:23-31

130. Enoch MA, Goldman D. Problem drinking and alcoholism: diagnosis and treatment. *American Family Physician*2002; 65:441-54

131. Pilling S, Strang J, Gerda C. Psychosocial interventions and Opioid detoxification for drug misuse: summary of NICE guidance. *British medical Journal* 2007; 335: 203-5

132. Lubman DI, Yucel M, Hall WD. Substance use and the adolescent brain: A toxic combination? *Journal of psychopharmacology* 2007; 21: 792-4

133. Kingston AH, Jorm AF, Kitchener BA, Hides L, Kelly CM, Morgan AJ, et al. Helping someone with problem drinking: mental health first aid guidelines – a Delphi expert consensus study. *BMC Psychiatry* 2009; 9: 79.

134. Mental Health First Aid Training and Research Program. *Helping Someone With Problem Drinking: Mental health First Aid Guidelines.* Melbourne: Orygen Research Centre, University of Melbourne; 2009. Available from: http://www.mhfa.com.au/Guidelines.shtml

135. Mental Health First Aid Training and Research Program. *Helping Someone With Problem Drug Use: Mental Health First Aid Guidelines.* Melbourne: Orygen Research Centre, University of Melbourne; 2009. Available from: http://www.mhfa.com.au/Guidelines.shtml

136. Prochaska JO, Velicer WF, Rossi JS, Goldstein MG, Marcus BH, Rakowski W, et al. Stages of change and decisional balance for 12 problems behaviours. *Health Psychology* 1994; 13: 39-46

137. Mayer MA. SAMIRIS: Substance abusers who have both mental illness and mental retardation. *NADD Bulletin.*2001; 4: 92-9

138. Cunningham JA, Wild TC, Cordingley J, van Mierlo T, Humphreys K. A randomized controlled trial of an internet-based intervention for alcohol abusers. *Addiction* 2009; 104: 2023-32

139. Moos RH. Theory-based processes that promote the remission of substance use disorders. *Clinical Psychology Review* 2207; 27: 537-51

140. Kelly JF. Self-help for substance-use disorders: history, effectiveness, knowledge gaps, and research opportunities. *Clinical psychology Review* 2003; 23: 639-63

141. Mental Health First Aid Training and Research Program. *Suicidal Thoughts and behaviours: First Aid Guidelines.* Melbourne: ORYGEN Youth health Research Centre, University of Melbourne; 2008. Available from: http://www.mhfa.com.au/Guidelines.shtml.

142. Kelly CM, Jorm AF, Kitchener BA, Langlands RL. Development of mental health first aid guidelines for suicidal ideation and behaviour; a Delphi study. *BMS Psychiatry* 2008; 8: 17

143. Giannini MJ, Bergmark B, Kreshover S, Elias E, Plummer C, O'Keefe E. Understanding suicide and disability in three major disabling conditions: intellectual disability, spinal cord injury and multiple sclerosis. *Disability and Health Journal.* 2010; 3: 74-8

144. Australian Bureau of Statistics. *2007 Causes of Death Australia.* Canberra: ABS; 2009. p. 1-92

145. Rudd MD, Berman AL, Joiner TE, Nock MK, Silverman MM, Mandrusiak M, et al. Warning signs for suicide: theory, research, and clinical applications. *Suicide and Life-Threatening Behavior.* 2006; 36: 255-62

146. Kelly CM, Jorm AF, Kitchener BA, Langlands RL. Development of mental health first aid guidelines for deliberate non-suicidal self-injury: a Delphi study. *BMC Psychiatry* 2008; 8: 62

147. Mental Health First Aid Training and Research Program. *Non-suicidal Self-injury: First Aid Guidelines.* Melbourne: Orygen Youth health Research Centre, University of Melbourne; 2008. Available from: http://www.mhfa.com,.au/Guidelines.shtml

148. Meltzer H, Lader D, Corbin T, et al. *Non-fatal Suicidal Behaviour Among Adults Aged 16-74*. London: The Stationery Office; 2002

149. Macaulay F, Heslop P. *Hidden Pain? Self-injury and people with learning disabilities.* Bristol. Available from: http://www.selfinjurysupport.org.uk/files/docs/hidden-pain/hidden-pain-order-form.doc

150. Whitlock J, Eckenrode J, Silverman D. Self-injurious behaviours in a college population. *Pediatrics* 2006; 117: 1939-48

151. Kelly CM, Jorm AF, Kitchener BA. Development of mental health first aid guidelines for panic attacks: a Delphi study. *BMC Psychiatry* 2009; 9: 49.

152. Mental Health First Aid Training and Research Program. *Panic Attacks: First Aid Guidelines.* Melbourne: Orygen Youth health Research Centre, University of Melbourne; 2008 Available from: http://www.mhfa.com.au/Guidelines.shtml

153. Salkovskis PM, Clark DM, Gelder MG. Cognition-behaviour links in the persistence of panic. *Behaviour Research and Therapy* 1996; 34: 453-8

154. Mental Health First Aid Training and research program. *Traumatic Events: First Aid Guidelines for Assisting Adults*. Melbourne: Orygen Youth Health Research Centre, University of Melbourne; 2008. Available from: http://www.mhfa.com.au/Guidelines.shtml

155. Roberts NP, Kitchener NJ, Kenardy J, Bisson J. Multiple session early psychological interventions for the prevention of post-traumatic stress disorder. *Cochrane Database of Systematic Reviews* 2009: 8; CD006869