Disability Guide in Plain English:

Supporting people with disability who have experienced complex trauma

Blue Knot Foundation

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empowering recovery from complex trauma

Blue Knot Foundation 2021

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www.blueknot.org.au

Disclaimer

This is a summary guide for people who work in supporting roles in the disability sector. The guide provides information to support decision making and is based on the best available evidence at the time it was developed.

Acknowledgements

Blue Knot Foundation (BKF) respectfully acknowledges the traditional owners of country throughout Australia and their continuing connection to land, waters and community. We pay our respects to First Nations peoples and their cultures, and to their elders, past, present and future. We acknowledge their strength and resilience to thrive as sovereign owners and are honoured to journey with them on the path to healing and reconciliation.

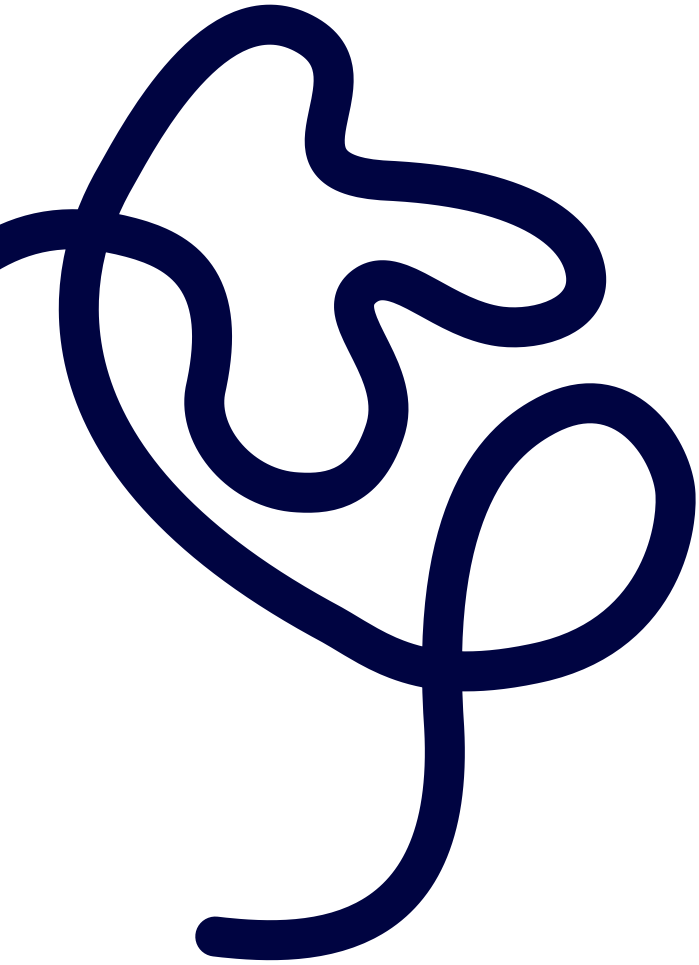
Blue Knot Foundation (BKF) is the Australian National Centre of Excellence for Complex Trauma. It empowers recovery and builds resilience for the more than five million adult Australians (1 in 4) with complex trauma experiences. It also supports their families and communities. Blue Knot is a leader in thought, policy, training and practice in complex trauma and trauma-informed services. In 2019 it was funded to deliver the National Counselling and Referral Service supporting people engaging with or impacted by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This service now also supports people with disability with complex trauma experiences – violence, abuse, neglect and exploitation. It also supports their caregivers, advocates and service providers.

We gratefully acknowledge the Department of Social Services who funded the development of this guide. This guide will help support the disability sector to support people with disability to overcome the barriers they often face to social justice and participation. The guide was developed over a 12 month period and is a supporting document to the full set of *Disability Guidelines for Trauma-informed Practice*: *Supporting People with Disability who have experienced Complex Trauma.* You can find the full guide on the Blue Knot website at www.professionals.blueknot.org.au/resources/publications/supporting-people-with-disability. Blue Knot consulted and worked closely with people with disability, caregivers, advocates, support workers and disability services. The rich insights provided have informed this guide, extending knowledge from the relevant literature to identify practice tips and resources to enable better responses to people with disability who have experienced trauma.

We would like to acknowledge and thank the many people with disability, trauma survivors, caregivers, support workers, and advocates from across Australia who so generously shared their experiences for this guide. They provided useful feedback which we have included. We hope the guide will build useful knowledge and skills for people supporting people with disability who have experienced trauma.

We would also like to thank and acknowledge the disability organisations on the reference group for their support and guidance over the past 12-months:

Special thanks to Mary Mallett and Siobhan Clair (Disability Advocacy Network Australia), Harry Lovelock and Katherine Shoemark (Mental Health Australia), Emma Bennison (Blind Citizens Australia), Maeve Kennedy and Miranda Cross (Children and Young People with Disability Australia), Liz Reid and Jennifer Cullen (NDIA Independent Advisory Council), Catherine McAlpine (Inclusion Australia), Vanamali Hermans (Women with Disabilities Australia), Dr Anita Strezova and Daniela Correia (Multicultural Disability Advocacy Association), Kelly Treloar (First Peoples Disability Network), Ross Joyce (Australian Federation of Disability Organisations) and Stephen Kilkeary (People with Disability Australia). We would also like to acknowledge the important work of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This guide also includes the voices of people with disability speaking to the Commission. It would not have been possible to develop this guide for the disability sector without this input.



About this document

This document is a plain English version to the Guidelines for Trauma-Informed Practice: Supporting People with Disability who have Experienced Complex Trauma. It is for people who support people with disability who may not know much about trauma or about the experiences of people with trauma. It is written in plain English to make it as accessible as it can be. To help, important information and practice tips are highlighted in boxes with an icon. For more information, see the *Disability Guidelines for Trauma-Informed Practice*: *Supporting People with Disability who have Experienced Complex Trauma* at www.professionals.blueknot.org.au/resources/publications/supporting-people-with-disability.

Language and terms

There is a list of some of the words used in this document at the end. Those words are in bold and dark blue text. Their definitions are in the word list at the back of this guide.

Case studies

A number of case studies are used in this document. These are used to describe the different needs and experiences of people with disability with complex trauma experiences. Some of these case studies are from what people with disability have told the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. We have changed the names so the person cannot be identified. We have made notes on these case studies to recognise the people involved. We have written some case studies to help explain what we are saying. They are made up and the reference group helped us make them up.

Content warning

Please note that this document has information in it that can be upsetting.

This is because it talks about violence, abuse, neglect and exploitation of people with disability. It also talks about suicide and hurting yourself. If you have any difficult feelings after reading it, please get support.

You may have your own support system you can access. You can also get support through the Disability Gateway by phoning 1800 643 787 between 8am-8pm Monday to Friday.

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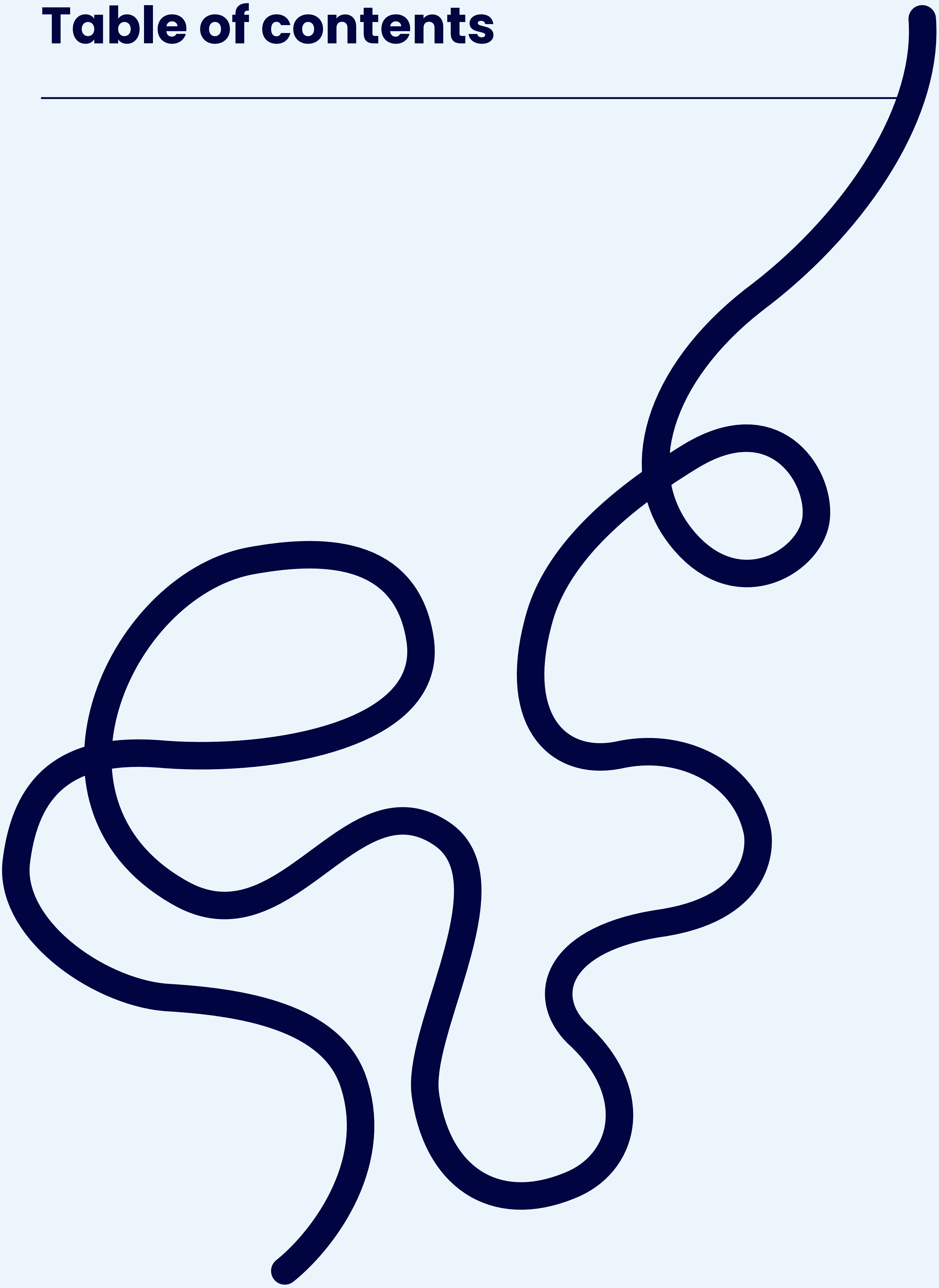


Disability and human rights

The United Nations Convention on the Rights of Persons with Disabilities 2008 (UN Convention, 2008) says how people with disability should be treated. You can read more about the convention at www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.

It is important to be ethical in how you live and work. Being ethical helps us look after a person's rights. This is very important for people with disability. It is also important for people with trauma experiences. Everyone should treat everyone else fairly and properly.

Caregivers, support workers and **advocates** have a duty to provide the best support they can. This means meeting the needs of the people they are supporting. It also means doing whatever they can to not hurt the other person. This means not hurting them physically or sexually and not hurting their feelings or finances. Whenever another person hurts someone, the person who is hurt has the right to tell others about it and make a complaint. Being ethical also means supporting people to talk about things that are bothering them or to make a complaint or get an independent advocate to help them.

Things to know – UN Convention on the Rights of Persons with Disabilities

The UN Convention is about the human rights of people with disability. It says that:

- Every person with disability should have respect.
- Every person with disability should be treated with dignity.
- Everyone should be treated with respect and dignity, and that it doesn't matter what their gender, sexual preference, religion, culture and values are.
- People with trauma experiences should be treated with respect and dignity.

Social model of disability

> **“The social model sees ‘disability’ is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others.”**

www.pwd.org.au/resources/disability-info/social-model-of-disability

Disability is sometimes seen as a problem or something that needs to be fixed. People with disability are sometimes seen as people who are different to ‘normal’. This is because we used to think about disability like a medical problem. We used to focus on what a person cannot do, rather than what they can do. This can exclude people with disability. It can mean that the needs of people with disability are not taken seriously. This can make it more likely for people with disability to experience violence, abuse, neglect and trauma. It can also mean that places like schools, hospitals, courts or police do not listen to people with disability telling them that they have been abused. This means that people with disability sometimes cannot make a complaint or get justice.

The social model of disability looks at what a person can do. It sees disability as a social issue. It says that we see disability and people with disability the wrong way. Disability is not about a problem with the person or the disability at all. When we stop seeing disability or the person with disability as a problem, we can make things better for people with disability. Disability is about diversity or difference, and we should honour these. But some of these differences can mean barriers for people. The social model of disability helps us see these barriers for people with disability. These barriers can stop people being a part of the community and having a full life. Supporters can help people with disability manage the barriers they face.

Some people with disability experience discrimination because other people do not understand disability. Some people have attitudes and beliefs about what people with disability can and cannot do. These people might not treat people with disability well because of these attitudes or beliefs.

People with disability also might face physical or environmental barriers. Barriers include steps or curbs that a person with mobility issues cannot use. Or environments that do not have wheelchair ramps or enable companion animals. Lack of transport options or access to parking might also be a barrier.

People with disability may also face language and communication barriers. It is important to try and understand how people communicate. Some people might need an interpreter or special technology to communicate. Some people might use drawing or body movements to communicate. Some people prefer certain words to be used or not used. Some people prefer person-first language (e.g. 'person with disability'). Some people prefer identity-first language (e.g. 'disabled person'). It is important to ask the person what language they prefer. For more information about person-first language visit the Australian Network on Disability website at www.and.org.au/pages/inclusive-language.html.

People with disability regularly face social or cultural barriers too. Some social barriers stop people from going to work or school or getting money. These barriers can also make it hard to have friends and partners. This can make people feel very lonely. Some cultural barriers can make people feel misunderstood by people from other cultures. Support must be free from racism and feel welcoming to people of different cultures.

People with disability may also face systemic barriers. This is when a service or system is too complicated or hard to use. Or when support is provided in a way that is not helpful or does not properly suit the person. Such as making young people with disability live in an aged care facility because it is the only place that they can get the supports they need. Or providing services in places and at times that people cannot get to them. Or not making changes that can help people in the workplace.

Attitudinal barriers

- Helping workers to have helpful attitudes about people with disability.
- Providing training and support to stop discrimination.
- Helping workers to understand and respect different cultures.

Physical or environmental barriers

- Making sure people with disability can safely get to the service and home again.
- Making sure the service environment is safe and comfortable for people with disability.
- Making sure people with disability can bring what they need to the service, like wheelchairs, communication devices and companion animals.

Language and communication barriers

- Using lots of different ways to communicate.
- Making interpreters, technology that helps communication, or having workers that speak different languages available.

Social and cultural barriers

- Making sure there is no racism at the service.
- Supporting people with disability to make and keep friends and partners.
- Helping people to not feel ashamed or embarrassed about coming to the service.

Systemic barriers

- Helping people to find pathways when the system is not working properly for them or is too complicated or hard to use.

Disability and trauma

Many people with disability have experiences of trauma. It is hard to know the number of people with disability who have experienced trauma. Trauma is more common in people with disability than people who do not have disability. In Australia, people with disability are two times more likely to experience violence as people who do not have disability. This means that two out of every three people with disability have experienced violence. Women with disability (age 18 to 64) are two times more likely than women without disability to experience sexual violence (Sutherland, Kavanagh, Llewellyn, Byars, Krniacki & Hargrave, 2020). Children with intellectual disability or who have barriers to communicating are more likely to experience trauma (Hoch & Youssef, 2019). While many people experience trauma at home, many people with disability experience abuse and neglect in services and when they get support.

Power is often not the same between the service, workers and the people who access services. This can make abuse and violence more likely. Some systems make more barriers for people with disability. These barriers can make abuse and neglect more likely. This is because organisations often do things to suit the organisation, and not the person. Some workers in services abuse their power. Some workers do not behave in an ethical way. Betraying trust and keeping secrets are common in some organisations. Organisations that keep secrets and do not let other people see what they do are more likely to abuse their power. These organisations often do not hold people hurting other people responsible. Detention centres, prisons, group homes, residential facilities are all places in which there has been abuse of power. People with disability have often been badly treated in many of these places. In some places, people with disability are still abused and harmed.

Trauma can change what a person does. Many people do not understand trauma or how it affects people. Not understanding can make more barriers for people with disability who have experienced trauma. Many people who have experienced trauma find it hard to speak about the abuse. Many people telling someone about abuse for the first time are not believed. Children and some people with disability who have barriers to communicating, or who live with intellectual disability have more barriers to speaking about abuse. Sometimes, people with disability are not understood or believed when they tell people they have been abused. This is because many people wrongly think that people with disability are not able to tell things as they are.

Things to know – Disability and trauma

- Sometimes trauma can cause disability.
- Many people with disability experience trauma.
- Many people find it hard to talk about trauma.
- It can be hard for some people with disability to talk about trauma because of different barriers.
- This can mean that some people with disability may not tell anyone about their trauma.
- This is why people who support people with disability need to understand more about trauma.
- It is important to understand about the different barriers for people with disability who have experienced trauma.
- It is important to notice when a person you are supporting is distressed, trying to cope with trauma, or experiencing the effects of trauma.
- It is important to know how to support someone in a way that helps and does not make the trauma worse.

Understanding trauma

Trauma is a "state of high arousal in which normal coping mechanisms are overwhelmed in response to the perception of threat"
(Cozolino, 2002:270)

We all have different experiences. Some experiences change us. Some experiences change us in a good way and other experiences harm us. Trauma is one of the experiences that can harm us. Trauma can happen once, or it can happen many times. Trauma is the word used to describe the experience. Trauma experiences are common. We all know someone who has experienced trauma, even though the person may not have told us about their trauma. Each of us can experience trauma and so can a friend, a family member or a work colleague.

The word trauma also describes the effects of extreme stress. The extreme stress of trauma overwhelms a person's ability to cope. This can cause further harm. Life-threatening events are traumatic. But not all traumatic events are life-threatening. People can experience trauma even when their life is not threatened or when they just think they may not survive the event (Cozolino, 2002). For some people this happens over and over.

Trauma is not always about the size of the event/s. While some experiences would be too much for most people, other experiences are different. Some things that seem little to some people can harm others. People who have experienced trauma have many different reactions to the trauma. Each person's experience is individual. With trauma, it is not only what happened that is important but also how, where and why it happened.

Trauma can affect us at the time of the event. It can also affect us over time. If we do not get the right support, trauma can affect us throughout our life. Not being able to get support can make it harder for us to protect ourselves from being harmed again. It can make it harder to understand or explain the experience of trauma to ourselves or other people.

Things to know - Trauma

- Trauma is the result of a violent or otherwise very stressful event or series of events.
- The effects of trauma are not always about the size of the event. The effects can happen for a lot of reasons.
- Trauma can cause physical or emotional harm.
- Trauma results from a threat to life, or the perception of threat.
- Trauma can affect the way we think, feel, behave, connect with other people and what we believe (SAHMSA, 2012).

What is complex trauma?

There are lots of different types of trauma. Some people experience trauma when they do not have someone they can rely on to care for them when they are a child. Some people experience trauma when the person looking after them during childhood does not recognise and respond to what they need a lot of the time.

Some people experience trauma at an important time in their life as a child. For example, this can happen when they are first learning how to walk or talk. Sometimes people experience just one event that causes trauma. This might be a natural disaster such as a bushfire or flood or a single act of violence from another person.

Some traumas are experienced across entire generations. For example, by great grandparents, grandparents, parents and children. First Nations people have had generations of trauma. This includes being forced to move from home, having children taken away, being forced to live life differently and being discriminated against (Lowitja Consulting, 2018). Some people experience traumatic events throughout their whole life. This is called complex trauma.

Complex trauma is repeated and ongoing trauma. It is cumulative or builds up and happens when one person or several people harm another person. When trauma starts early in childhood it can be especially damaging. The impacts can continue for a long time and affect people in many areas of life.

Content warning

This case study contains information that may be upsetting for some people.

This is because it talks about violence, abuse, neglect or exploitation of people with disability. If you have any difficult feelings after reading it, you may want to reach out for support.

You can be provided with information and connected to counselling services through the Disability Gateway by phoning 1800 643 787 between 8am-8pm Monday to Friday.

Case study – Ralph*

Ralph is a First Nations man in his thirties. He is Deaf and has depression and anxiety. He has been abused, bullied, harassed and discriminated against all his life because of his disability:

“In life I had no support and all this experience impacted my depression and anxiety. I was a survivor of suicide, twice… all this trauma of life… and the missed opportunities of good education… good jobs and good future.”

Ralph was abused by his foster parents during the 1990s:

“They both hurt me. When I was [9] and [10] my foster father tried to choke me and my foster mother tried to break my finger. They both hit me… It was so traumatic. I had to live it until I was out of care when I turned 18. At the time I didn’t know any services or education on where to get help. I still live in pain from this.”

The abuse continued at school. In primary school the teachers restrained him almost every day. In high school, the teachers told him that he would not be able to go to university to get a social work degree, because of his disabilities. He was not allowed to choose the subjects he wanted to study – those decisions were made by his teachers:

“I wasn’t able to make subject decisions like other mainstream students… I went to TAFE and did a community service and business management course and completed it.”

When Ralph was employed, his employers and co-workers harassed and bullied him because of his disabilities. His employers did not want to make reasonable adjustments to his work environment:

“I tried to advocate myself but the battle was difficult to win over. I worked at a coffee shop in [a] support[ed] employment program… they decided not to pay me full wages (70 per cent), which I didn’t agree. The employer said it was because of my learning disability… The boss clapped in my face and yelled at me… and had no attention in learning about my disability. I had anxiety meltdown at this job. I brought in my psychologist to try and manage things but when my psychologist left my work the supervisor had a go at me, saying ‘how dare you bring your psychologist in my workplace’. I had no choice but to resign”.

Ralph felt left out of his culture because of his disability and trauma:

“There is not enough education or awareness out into the community. It feels like we are hopeless and people don’t understand the life we live.

We need to work on equality and [be more] inclusive in Australia... We need more disability advocates like myself... We also need politicians to listen to us.”

*Name changed and some details removed to protect people’s identities. Narrative based on a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Things to know – Complex trauma

- Trauma can happen one time as a single event.
- Trauma can happen lots of times or be ongoing and extreme – it is called complex trauma.
- Complex trauma is more common than one off trauma and can cause more harm.
- Some people experience trauma right through life, as a child and also as an adult.
- Some people experience impacts from the trauma right through life.

What happens when you experience a traumatic event?

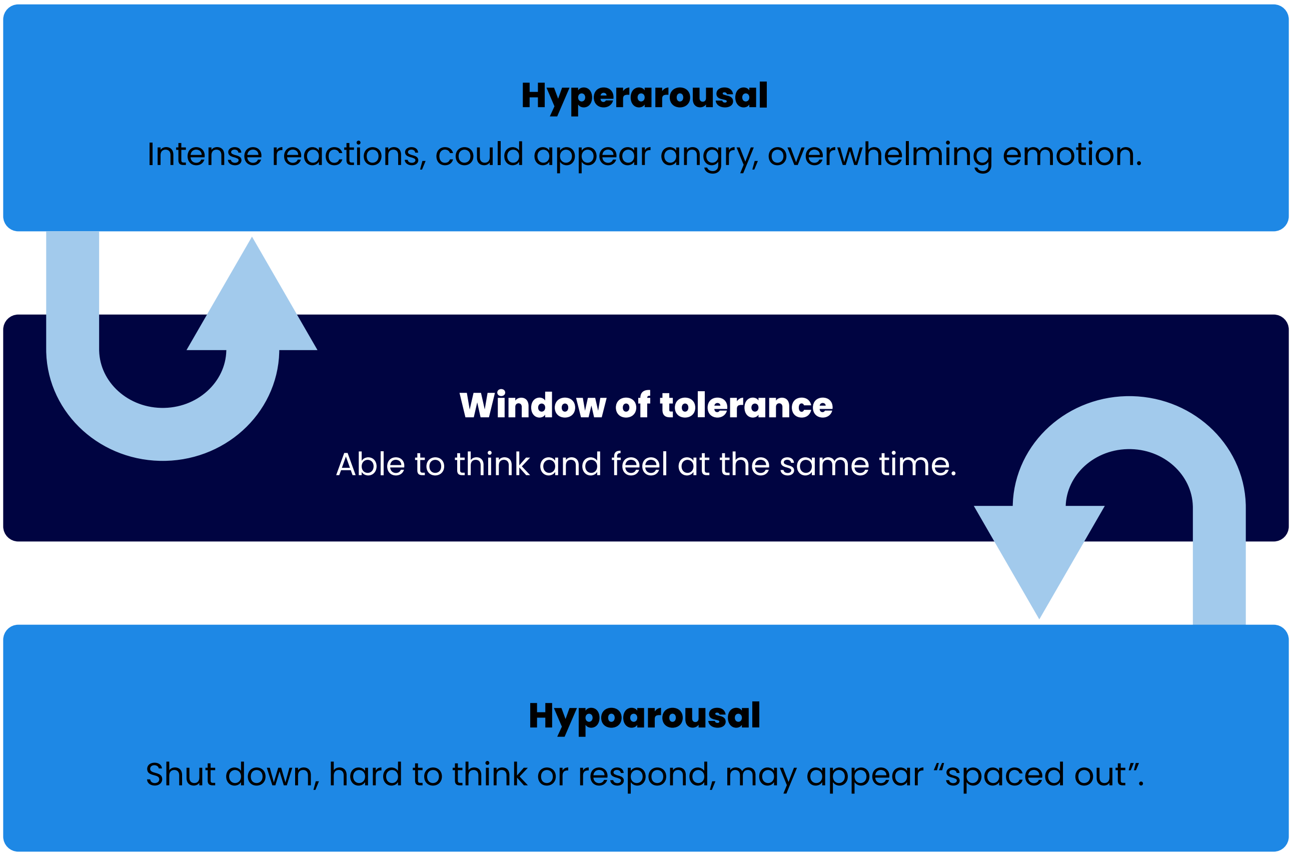
When something happens that scares us, we cannot always control what we do or how we respond. This can happen at the time we are scared. It can also happen after the scary event is over. This helps us to survive dangerous or scary things.

After an event that scares us, many people experience things that remind them of the scary event. These are called triggers. Triggers may be a person shouting or getting too close. Certain times of the day or night can be a trigger. Bedtime can be a trigger. The trigger may be something that happens at the same time of the day. For example, room checks. Some dates trigger some people. Triggers can be tall women or men with beards. It can be contact with our family. It can be anything that make us feel unsafe and reminds us of the scary event. Triggers make us feel upset.

When we experience triggers, we can feel scared again and become jumpy or feel like we are ‘on high alert’. We call this hyperarousal. It is easy to tell when a person is hyperaroused. The person may yell and seem angry or aggressive. The person may shake, sweat or have wide pupils in their eyes. People can feel very scared and stressed when they are hyperaroused (even if the person might look angry).

Sometimes triggers can make us feel ‘shut down’ or go numb. This is called hypoarousal. It is not so easy to tell when someone is hypoaroused. The person may find it hard to respond to other people. The person might look ‘spaced out’ or ‘on autopilot’. The person may look like they are not trying. The person might be called ‘resistant’ or ‘difficult’. They may be forced to do things, which may make the person react more. If the person is hypoaroused, challenging the person can cause more trauma. People can feel as though they are dreaming or confused when hypoaroused.

Fig 1: Window of tolerance



Hyperarousal

Intense reactions, could appear angry, overwhelming emotion.

Window of tolerance

Able to think and feel at the same time.

Hypoarousal

Shut down, hard to think or respond, may appear “spaced out”.

Practice tip - How to support people who are hyperaroused and hypoaroused

Here are some strategies that you can use to support people when they are hyperaroused or hypoaroused:

- Recognise that being hyperaroused or hypoaroused is a distress or fear response.
- Acknowledge the person’s response (‘I can see you are…’).
- Offer support (‘Would you like me to support you to…’).
- Suggest that the person takes a ‘rest’ break. Suggest having a stretch, go for a walk, or take some time outside.
- Help the person to become aware of their surroundings.
- Help the person tune into their senses – hearing, seeing, smelling, touching and tasting.

If a person becomes hyperaroused (i.e. jumpy, sweating, wide pupils in their eyes, raised voice, speaking fast, face becomes red or flushed):

- **Here and now grounding** - Support the person to focus on the present. What do they need now? What do they have to do now?
- **Physical grounding** - Suggest the person gently stamps their feet on the ground or does something physical like going for a fast walk (if safe to do so).
- **Breathing** - Suggest the person takes some long and slow breaths.
- **Sensory grounding** - Suggest the person holds a calming object – something that is meaningful to them and helps the person soothe through using one of their senses e.g. photos, music or friend's voice, essential oils, favourite scent, woolly socks, teddy bear etc.
- **Inner experience grounding** - Support the person to notice what is happening in their body (e.g., sweating, shaking, feeling hot etc.) Notice what is similar and what is different to the way the person normally feels).

If a person is hypoaroused (i.e. 'spaces out', glazed eyes, on 'autopilot' or 'shut down'):

- **Here and now grounding** - Support the person to focus on the present moment.
- Remind the person that they are safe and give them the time and space needed. Speak calmly and slowly to support the person to be aware of where they are ('I am xx; it's Tuesday morning; we're sitting in a café…').
- **Physical grounding** - Suggest a simple stretch (the focus should be on the movement and not on what they are feeling inside.
- **Sensory grounding** - If the person cannot feel their body, suggest they rub their arms and legs to help them feel where their body starts and ends.
- If the person is sitting down, and if they are able, suggest they stand up for a moment (and stand up with them) - support them to focus on the movement and not on the feeling inside.
- Suggest the person puts a blanket or towel around them so they can feel it on them.
- Support the person to focus outside of themselves by helping them to connect to their different senses.

For more detailed trauma-informed support strategies, visit the *Disability Guidelines for Trauma-Informed Practice*: *Supporting People with Disability who have Experienced Complex Trauma* on the Blue Knot Foundation website at www.professionals.blueknot.org.au/resources/publications/supporting-people-with-disability.

Some people dissociate when triggered. We all dissociate sometimes. Examples are daydreaming or focusing hard on doing something. This is normal and does not cause a problem for the person. However, dissociation caused by trauma can make it hard to do things. Dissociation is like extreme hypoarousal. Sometimes dissociation is obvious. More often it is hard to notice. We do not always know that we have dissociated. Sometimes we might know that we have lost some time and we have no memory of what happened during that time. Or how we arrived at a certain place.

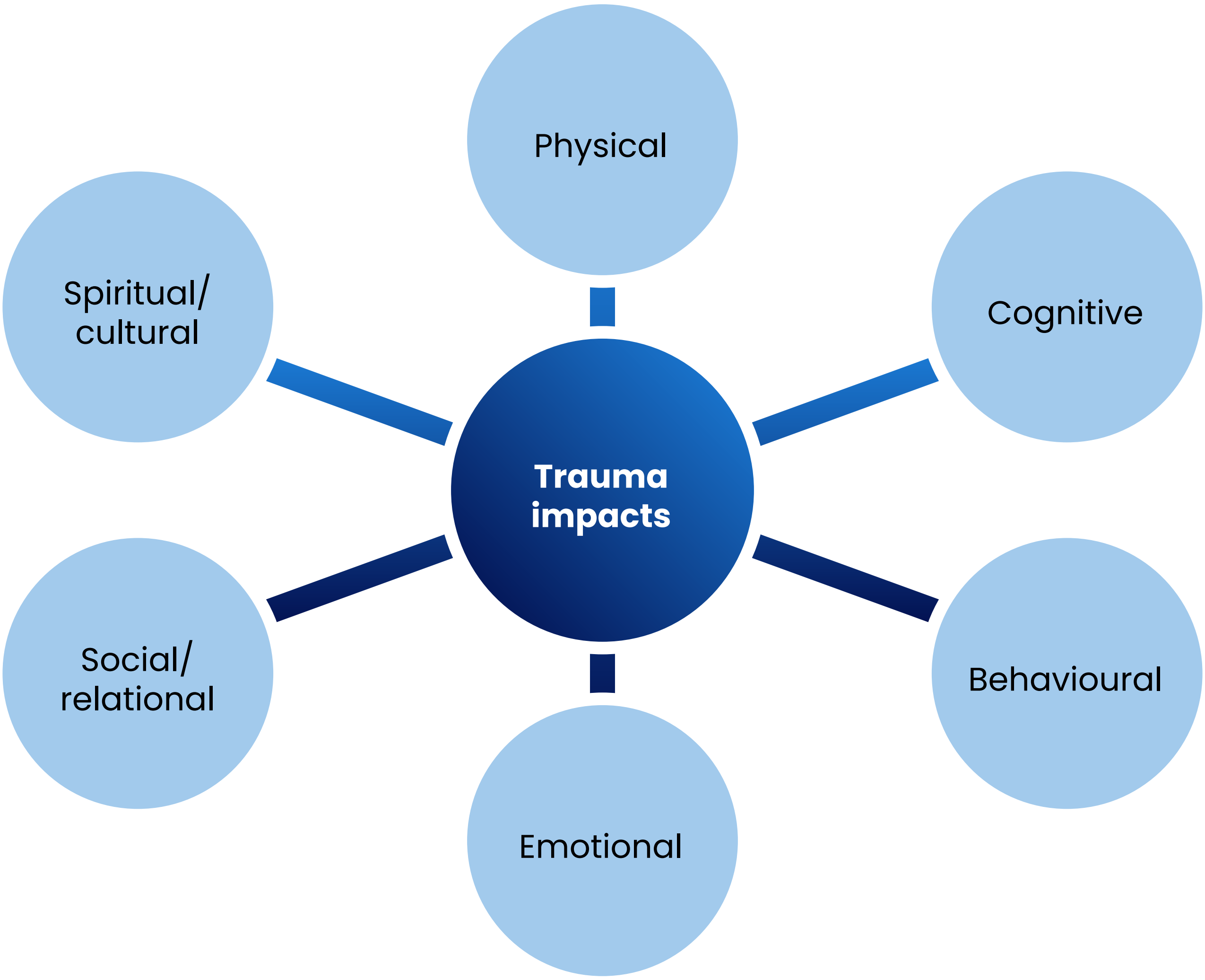
Sometimes we experience flashbacks or re-enactments. These are when we relive trauma memories. They are sudden and we do not expect them. They often come with strong feelings like terror and distress. They can also come with strong sensations and body movements. When we are reminded of traumatic events, it can feel like past experiences are happening in the present. We start to behave like we did during the trauma. Even when there are no communication barriers, it can be hard to put flashback experiences into words.

Things to know – Trauma and stress response

- Trauma is different to everyday stress - it stops us being able to cope.
- People cannot always control how they respond to a traumatic event.
- Triggers are reminders of a traumatic event.
- Triggers can cause hyperarousal and make a person become jumpy and feel 'on high alert'.
- Triggers can cause hypoarousal and make a person feel 'shut down' or go numb.
- Trauma can cause severe dissociation.
- When people experience flashbacks or re-enactments they can feel like they are experiencing the past traumatic event in the present.

Complex trauma impacts

Fig 2: Impacts of trauma



Not everyone who experiences trauma experiences harm over a long period of time, but many people do. Trauma can have a lot of different impacts. The impacts are different for different people but are mostly in these six categories:

1

Physical impacts

Complex trauma can cause injury and illness. As well as being physically harmed and injured, experiencing lots of trauma over a long time causes the body to release stress hormones or chemicals. These chemicals can make you more likely to get sick or have chronic diseases later in life. People with disability who have experienced complex trauma often have a lot of medical and physical health needs.

2

Cognitive impacts

Cognition is about thinking, understanding, learning and remembering. Complex trauma can interrupt how we remember things. Complex trauma can also make it hard to think clearly. Lots of trauma can also change the way we think about ourselves and the world around us. Some people who have experienced trauma have low self esteem because of the trauma experienced. Some people feel that the world and all other people are dangerous and not safe.

3

Behavioural impacts

People who have experienced complex trauma use different strategies to help them cope with the impacts of trauma. These can be behaviours such as hurting themselves, eating a lot, being aggressive, trying to not sleep, or having to do things over and over. People around them can see these behaviours and coping strategies as a problem. The coping strategies are sometimes labelled ‘behaviours of concern’.

The term ‘behaviours of concern’ is often used within the disability sector. A ‘behaviour of concern’ is defined as a behaviour: ‘of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion’ (Royal College of Psychiatrists, 2007, p. 10).

Understanding trauma can explain a lot of what is often labelled as ‘challenging behaviours’ or ‘behaviours of concern’. Sometimes people show their strong feelings through what they do. This can happen if the person has barriers to talking about the thought or feeling that came before the behaviour. Understanding the trigger to the behaviour can help you understand the person’s reactions and the behaviour. It can be hard to understand a person’s behaviour when the trigger is not noticed or understood. Sometimes, the person is punished for the behaviour. Sometimes support workers can find a person’s actions or manners challenging. Even though the person may not mean to be challenging. The person may be doing what they can to survive or to stop something from harming them.

Things to know - Behaviours

- Some things people do to cope with their trauma may be labelled ‘behaviours of concern’.
- The response to ‘behaviours of concern’ has often been to try and control them.
- It is important to think about why a person might be behaving in a certain way.
- If the reason for the behaviour is not understood, the person can be labelled as ‘uncontrollable’, ‘manipulative’, ‘attention-seeking’ or ‘psycho’.
- Labels and being called names hurts people and can make things worse.
- Often the main focus of treatment is the person’s behaviour.
- The person may be tied down or forced to take medication.
- It is not okay to punish a person because of their complex behaviour support needs.
- It is not okay to withdraw support because of what a person does.
- It is important to respond differently to people with strong feelings and complex behaviour support needs.

People tell us that something is not okay by the things they do. Behaviours are ways people communicate that there is something wrong in the environment it could be an abusive support worker, a caregiver who is not responding to their needs, or other problems that the person with disability cannot change. The behaviour needs to be listened to and understood.

4

Emotional impacts

Complex trauma can make it hard for a person to manage, express or feel strong feelings. Trauma from childhood can cause barriers that stop people learning how to manage strong feelings. Adults and children who have learnt to manage strong feelings can calm themselves and self-soothe. Many people who have experienced trauma become anxious or depressed (Fergusson & Mullen 2007). Some people try to manage strong feelings by numbing the feelings or trying to ignore them. Sometimes it might be helpful to not feel or talk about feelings in some situations or at certain times. Some people use alcohol, drugs, food, work, exercise, gambling or sex to help manage the strong feelings. This can make people seem out of control. Some people find it hard to feel anything and do different things to stop feeling so numb.

5

Social/relational impacts

Some people who have experienced complex trauma might find it hard to trust other people or have safe relationships. This is because other people have betrayed their trust or because their past relationships have not been healthy or safe. Communication and social barriers can make it even harder for some people with disability to make and keep trusting and safe relationships. This can happen for some people with intellectual disability, or who are on the autism spectrum, or with mental health issues. These barriers can make it hard for people to know how to trust (too much or too little). Sometimes people experience “othering” after a traumatic event. This is when you feel different from other people or are made to feel different because of the trauma.

6

Spiritual/cultural impacts

Trauma can make people feel disconnected from their culture. Many First Nations people feel this. Many have experienced the impacts of colonisation, marginalisation, forced removal of children, racism and intergenerational trauma. It can be similar for people who have escaped war or come to Australia wanting safety and asylum in a new country. Some people question their faith after trauma. Some question the meaning of life or their purpose in life. Some people try to cope by disconnecting from life. This can mean people miss out on living a full life.

The importance of cultural sensitivity

"A practice which respects, supports and empowers the cultural identity and wellbeing of an individual and empowers them to express that identity and have those needs met."
(Department of Health, 2004)

We do not need to be experts in other cultures to be culturally sensitive. We need to be empathic and curious about how people from different cultures are similar and how they are different. Cultural sensitivity can help us understand more about people from other cultures. Trauma and behaviour mean different things in different cultures. Our culture affects the way we experience things, including trauma. Sometimes people choose to do things differently. This does not mean that the person is making a bad decision.

The decision might be different because the person comes from a different culture or has different life experiences. When we find out about the different ways we experience things, we understand other people better. This helps us to better understand what a person does and why. When we understand how people from another culture do things we can change what we do and say to show our understanding. This shows that we respect the values of the other culture. It is also important to tune into each person's background, gender, disability, sexual preference, language and lived experience of trauma as well. We can become comfortable in another culture, while still honouring our own culture.

Things to know - Cultural sensitivity

- It is important to understand how culture might change a person's needs and experience of disability and trauma.
- Being culturally sensitive does not mean being a cultural expert.
- It means being open to understanding and noticing cultural differences.
- It means thinking about your own beliefs, values and assumptions.
- It reduces the risk of discrimination.

Identifying complex trauma

It can be very hard to know if someone has experienced complex trauma. Sometimes people have a good understanding of their experience of trauma and how they have been impacted. These people can often let other people know about it too. The person may not know all the details of the trauma experienced and that is okay. It is important to not ask for lots of details of a person's trauma experience. Or demand to know all the details about what happened. Talking about past trauma can be very upsetting.

Not everyone knows about their history of trauma or can tell other people about it. When supporting people with disability who have experienced trauma, you may recognise thoughts, feelings or behaviours that might be caused by trauma.

Things to know – Possible signs of complex trauma

Possible indicators of trauma include:

- Going between hyperarousal and hypoarousal all the time.
- Strong and overwhelming feelings.
- Triggers that seem to cause sudden changes in thoughts, feelings or behaviours.
- Times when a person is deeply dissociated and loses awareness of time or where they are.
- Experiencing flashbacks, re-enactments or reliving past traumatic events.
- Complex behaviours that may be labelled as 'behaviours of concern.

It is very important to understand that not all changes in behaviour or strong feelings are because of trauma. However, anything in the list above may mean that the person you are supporting has experienced trauma. In this case, it is best to encourage or arrange for an assessment with a trauma specialist and to get further support.

Helping recovery

Recovery from trauma is a process. Recovery depends on a lot of different things. One major thing is the support people receive. Sometimes people do not know how to respond when someone tells them about their experience of trauma.

Practice tip – Responding to a person who is telling you about their abuse or trauma for the first time

Here are some ideas about how to respond to a person who is telling you about an abuse or trauma experience for the first time:

- Support the person and show the person that you believe them. This can help them feel less alone. It can also stop them blaming themselves and help them to feel less ashamed.
- Accept what the person says to you and do not judge the person.
- Listen and pay attention to the person.
- Stay calm and show empathy.
- Reassure the person and validate their feelings.
- Use body language that shows that you are paying attention.
- Offer the person choices about what they can do next (e.g. continue or take a break).
- Try to manage your level of stress or upset and the other person's.
- Refer the person to the right places. This may include:
  - Medical services to treat an injury or get evidence to help show that the person was assaulted;
  - Counselling services (e.g. sexual assault or domestic violence service);
  - Police or services with a lawyer (e.g. to make a police report or get advice from a lawyer);
  - Emergency housing services;
  - Financial support services;
  - Independent advocacy service to support the person to make a complaint to the NDIS Quality and Safeguard Commission or other place that can help.

You can also help people with disability recover from trauma by noticing possible signs that they may have experienced trauma and providing support. People need good support to manage the impacts of trauma. People need to feel connected with others through community and culture. People also need empathy, understanding and respect. Everyone can work together to stop people, organisations and systems from causing more trauma and harm. All people can also grow through the experience of trauma. This is called post-traumatic growth.

Practice tip – You can help people with disability recover from trauma

Here are some ideas on how to help people with disability recover from trauma:

- Be empathic, understanding and respectful.
- Notice possible signs that a person has experiences of complex trauma.
- Try to identify and reduce possible triggers.
- Have supportive interactions to build healthy relationship (e.g. conversations, compassion and care) - it doesn't matter if the interaction is big or small. It all helps.
- Support people to manage the impacts of trauma.
- Support people to remain safe and prevent further harm.

Minimising trauma and re-traumatisation

`[M]any survivors have been re-traumatized by [workers] who had inadequate understanding and skills to treat complex trauma-related problems...'
(van der Hart, Nijenhuis & Steele, 2006:224)

Being trauma-informed is the best way to reduce the risk of extra trauma. We call this re-traumatisation. People are often re-traumatised when other people do not acknowledge their experiences of abuse and trauma. People are also re-traumatised when the impacts of what happened to the person are minimised or made to seem little. Some people try to speak out about what happened but are silenced or ignored. Some are not believed. A trauma-informed approach is open to the possibility of trauma. It acknowledges the effects of trauma and each person's experience.

Restrictive practices, restraints and seclusion have often been used to stop people with disability from doing certain things. This has been a way of controlling what is labelled as 'behaviours of concern' and managing complex behaviour support needs. Restrictive practices have been used way too much and used when they did not need to be used. This is now recognised as going against a person's human rights. People who have experienced trauma are often re-traumatised when restrictive practices, restraints and seclusion are used. This is because these strategies make the person feel like they have no power or control over what happens to them. These strategies can remind people of what it felt like when the trauma happened. Some people experience further trauma when restrictive practices are used. These practices are sometimes used in schools, homes, hospitals, prisons, and residential settings.

Restrictive practices include different ways of stopping people from doing things. Sometimes people hold people with disability down. This can traumatise the person or retraumatise them. Being restrained can trigger previous feelings of being trapped, forced to do something against your will and makes you feel like you have no power or control over what happens to you. Many people felt trapped during past abuse. Sometimes medication or drugs are used to stop people with disability doing things. Some people with disability are forced to do things they do not want to do. Some people in control punish people with disability. Some people may take things away as a punishment or stop people with disability from seeing or speaking to their family and friends. Sometimes people in charge may take away a person's mobile phone to stop them calling for help. Sometimes people are made to follow strict rules. Strict rules and coercive control take choices away from people. It is important to support people to make choices for themselves. Being restrained is just as abusive if it is called a restrictive practice. Misusing restrictive practices is not ethical and, in some situations, it is also illegal.

The use of seclusion is also re-traumatising. This is because it locks people away, separates them from others, and makes people feel isolated. Seclusion stops people from engaging and connecting with other people. This can be bad for a person's health and wellbeing. This means the person has no support to calm themself or comfort from others when they are distressed.

For more information on the national framework for reducing and stopping the use of restrictive practices, see *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* on the Australian Government Department of Social Services (DSS) website at www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-framework-for-reducing-and-eliminating-the-use-of-restrictive-practices-in-the-disability-service-sector or the NDIS Quality and Safeguards Commission website at www.ndiscommission.gov.au/regulated-restrictive-practices.

National Disability Services (NDS) also has information on their website about restrictive practices at www.nds.org.au/zero-tolerance-framework/considering-additional-risk.

The following case study is an example of the use of some restrictive practices. It also shows how understanding a behaviour (e.g. food to self-soothe) can help change behaviours without the need for restrictive practices.

Content warning

This case study contains information that may be upsetting for some people.

This is because it talks about violence, abuse, neglect or exploitation of people with disability. If you have any difficult feelings after reading it, you may want to reach out for support. You may have your own support system you can access.

You can also get support through the Disability Gateway by phoning 1800 643 787 between 8am-8pm Monday to Friday.

Case study - Lena*

When Lena arrived for her first shift as a disability support worker in a day centre, she expected it to be as advertised. **"On paper the roster of programs looked fantastic,"** she told us. Participants, some with high needs, could choose different activities – for example, cooking, sewing, woodwork and drama. **"They should have been enjoying their life, but they weren't."**

Instead, she was confronted with 32 people, some restrained, some wearing face guard masks and some lying on the floor. There were only two staff and Lena was told to **"get on with it the best you can"**. The restraints were **"the old-fashioned chairs with belts on them… and people that were ambulant… would be strapped in"**. The masks were forced on people to stop them spitting. Lena was shocked because **"the newer restraint laws would definitely have been in"**.

All of the residents displayed complex behaviours including physical violence, compulsive eating and absconding. All doors, windows and the kitchen roller door were locked. The man Lena supported was a compulsive eater. Food soothed him, and he knew the staff kept their chocolates in the office. One day the supervisor found him in the office and yelled at him to get out. When the man did not leave immediately, the supervisor grabbed him and physically removed him. Lena supported the same man at a community centre during the day where the kitchen was open and lunch boxes were left out. With Lena's gentle support he learned not to touch food that did not belong to him.

Lena also recounted supporting a woman living in a residential facility for 30 men and women. Half of the residents lived with disability and half had been recently released from prison. Doors were not locked. For people with no support it was a place of last resort, **"before homelessness"**.

The home kept 85 per cent of the residents' support pension for food, toiletries, and health expenses. Residents were supposed to be given the remaining 15 per cent but this woman was lucky to get $10 a week. Food was served at strict times and toiletries were restricted. Lena says, **"I had to go every week and ask for soap… tampons… shampoo"**. Laundry was done only twice a week, so clean clothes were an issue. Rooms were not cleaned. The residents' cigarettes were taken and kept in reception which was only open during the day.

*Name changed and some details removed to protect people's identities. Narrative based on a private session with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Practice tip – Reducing trauma and re-traumatisation

Here are some ideas about how to reduce the risk of trauma and re-traumatisation:

- Remember that trauma may be the cause of a person's reaction or needs.
- Show that you believe the person when they are telling you about their abuse for the first time.
- Take care to not silence, deny or minimise a person's experience of trauma.
- Let the person know that feeling upset is normal with trauma experiences.
- Try to understand a person's triggers and remove likely triggers (e.g. remove triggering posters, meet in safe locations, limit the number of times the person has to tell their trauma experience etc.)
- Give the person extra support or prepare the person for when they have to go into triggering situations.
- When a person is triggered, support the person to manage the way they feel.
- Do not use restrictive practice, restraints and seclusion unless they absolutely must be used.
- Give the person extra support to help them manage the trauma impacts if restrictive practices must be used.

Making a complaint and reporting

When a person experiences abuse, violence, neglect, or exploitation in a service, the person has the right to make a complaint to the service. Some services have a clear, fair and accessible complaints process. Other services do not. At times, an independent advocate may help support people to make a formal complaint. Individual advocates may also help to take the complaint further if the first response to the complaint was not okay.

For more information on how to make a complaint about an NDIS provider, visit How to make a complaint about a provider on the NDIS Quality and Safeguards Commission website at www.ndiscommission.gov.au/about/complaints.

Sometimes, a person may tell you about something that is criminal. For example, child abuse and neglect, or theft, or physical and sexual assault. You need to understand your legal responsibility to report criminal behaviour. Some professionals, such as police or psychologists, must report certain alleged criminal offences. Sometimes people can get into trouble or be prosecuted if they do not act or report a serious criminal offence. This is why it is important to know the laws in your state or territory. For example, there are laws about reporting child abuse and neglect in each state and territory of Australia. For more information on the laws in your state or territory visit *Child protection* on the Australian Institute of Health and Welfare website at www.aihw.gov.au/reports-data/health-welfare-services/child-protection/child-protection-legislation-by-jurisdiction.

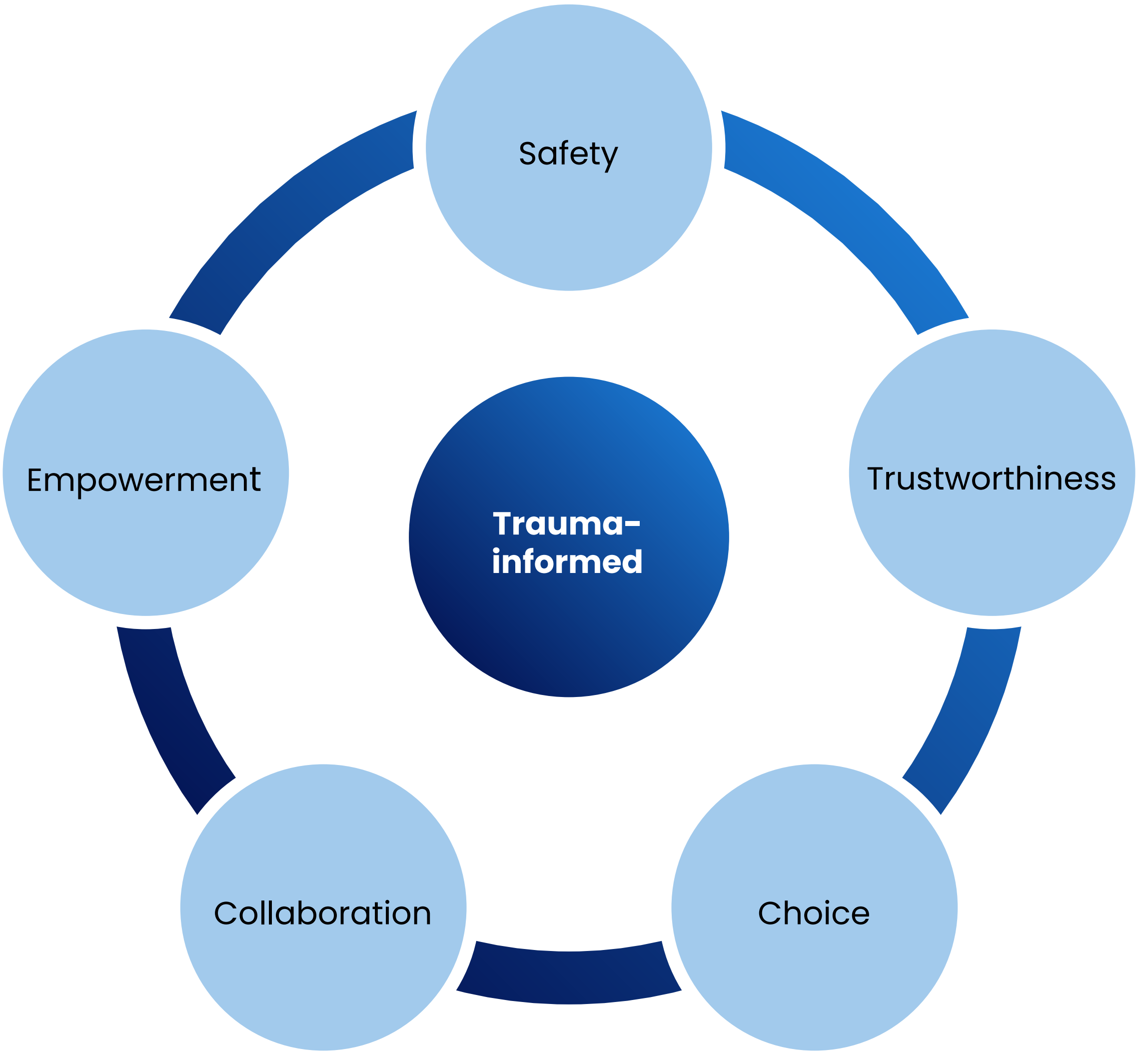
Reporting violence, abuse, neglect and exploitation against adults is a little harder. What you must and can report can depend on where you live, your work role, whether the person can report themselves or whether the person wants to report or not. Adults can usually choose for themselves about whether they want to report a criminal offence against them. If an adult has the capacity to make their own decisions and does not want to report violence, abuse, neglect or exploitation, that decision should be respected. If an adult does want to report to police, that decision should also be supported. A supporter might need to help make decisions or report abuse, neglect, exploitation or violence if the person is unable to do this by themself.

Being trauma-informed

"Trauma Informed Practice is not about the treatment of trauma or the symptoms, but rather a recognition that trauma experiences are a possibility for anyone"
(Kezelman & Stavropoulos, 2012)

Being trauma-informed means being aware of the possibility of trauma experienced by the people we support. It also means understanding how the experience of trauma might impact on the person's support needs. When we are trauma-informed, we support people to recover from trauma and reduce the risk of re-traumatisation. We do this by following the core trauma-informed principles in everything we do. The following practice tips show how we can do each of the five-core trauma-informed principles when we provide support:

Fig 3: Trauma-informed principles



Principle 1 -

Safety

When supporting a person to feel safe, we need to understand what does and does not feel safe for the person. This includes being sensitive to the person's trauma history and its impacts. We need to consider all the different types of safety, including personal safety, safety between people, safety in the environment, safe systems, and cultural safety. We need to think about both physical and emotional safety in each of these areas. A person's sense of safety can change easily. It changes with different people and experiences. It changes over time.

Practice tip – Establishing safety

Here are some ideas for how to support a person to feel and be safe:

- Is the person free from physical harm?
- Find a private space to meet the person - does the person feel comfortable in this space?
- Manage your own responses - they can help the person to feel safe or not.
- Show the person that you want to understand what they need.
- Pay attention to what your non-verbal communication is (e.g. how your body and face might be showing the person what you think).
- When the person is speaking or communicating, do not look away or interrupt.
- Listen compassionately - tune in and be present.
- It is okay to say: 'I don't know what to say'.
- Support the person to feel in control.
- Value the person.
- Support the person to express their feelings and manage strong feelings.

Principle 2 –

Trustworthiness

Many people with disability who have experienced trauma caused by other people feel very betrayed. When we have been betrayed, we find it difficult to trust other people and services. We need to be patient with people when we are building trust. It is important to be reliable, consistent, and predictable. We can build trust by maintaining confidentiality and privacy. Supporters need to tune into the needs of the people receiving support. This means being able to pick up on any hints that may mean the person does not trust you or the service. It is important to acknowledge to the person that trust can take time. Trust needs to be earned and can be easily broken.

Practice tip – Establishing trustworthiness

Here are some ideas for how to establish trustworthiness:

- Build respectful relationships with healthy boundaries.
- Honour privacy and confidentiality.
- Be open and transparent – no secrets or whispering.
- Be enthusiastic and real.
- Be clear about what you are going to do and provide accurate information.
- Do what you say you will do. If you cannot do it, be honest and tell the person.
- If you make a mistake, own it and apologise.
- Be consistent and reliable.

Principle 3 –

Choice

Many people with disability have not had much choice in life. People with trauma experiences also had no choice about the abuse or violence they experienced. Providing choice is not just about offering choices. It is being creative with options. It is about providing new opportunities.

Practice tip – Providing choice

Here are some ideas for how to provide choice:

- Support as much choice as possible.
- Acknowledge the person's point of view.
- Honour the person's interests even if they are different to yours.
- Provide the person with the information needed to make informed choices and consent.
- If you cannot allow a person's choice, be compassionate and person - centred when you explain the reasons for this.

Principle 4 – Collaboration

Collaboration means doing something ‘with’ a person rather than doing something ‘for’ or ‘to’ the person. We engage more effectively with people when we cooperate with them. Always try to reduce any power imbalances between you - the person providing support and the person receiving support. The person receiving support is the expert in their own life. The person receiving support must play a key role in making decisions about what they need and the support they receive. Collaboration also means working with the person’s support network. It means working and talking together and sharing information with their other supporters. Care and support are more helpful when well coordinated.

Practice tip – Promoting collaboration

Here are some ideas for how to promote collaboration:

- Do not assume that the person cannot make their own decisions.
- Accept the person’s decisions, even if you do not agree with them.
- Do not assume that the person cannot act for themselves.
- Try and recognise when the person may need your support in making decisions or acting for themselves.
- Follow the person’s lead and go at their pace.
- Be welcoming and inviting - support the person to feel comfortable.
- Do not try and control the relationship – power in the relationship should be shared equally.
- Promote mutual relationships.
- Be flexible, responsive and accessible.
- Involve the person in making decisions about who should and should not provide them with support.

Principle 5 –

Empowerment

Trauma often occurs when a person makes you feel like you have no power over what happens in your life. Trauma also causes people to feel like they have no power. Trauma can damage a person's self-esteem and their confidence. Getting power back supports recovery from trauma. Supporting a person to build self-determination is very important. It might include supporting a person to find a job, stable housing, or live independently. It might include removing the barriers that prevent people from participating in the community. Or to provide opportunities to learn and develop skills and strategies. It requires a careful balance between advocating for a person when they want and need you to. But also, not doing something for the person if the person can do it themselves.

Rescuing a person does not support the person to build their own strengths and capabilities and can stop them from feeling like they have power.

Practice tip – Building empowerment

Here are some ideas for how to support a person to build their power:

- Support the person to choose what they want to do and when.
- Do not decide for the person.
- Provide the person with the information they need.
- When a person has the right information, they can make informed decisions.
- Do not force your decisions on anyone.
- Support the person to have personal control.

Supporter wellbeing

People who provide care or support to others can sometimes look after the needs of others over their own needs. It is important that supporters take care of their own wellbeing (Allman, 2015). Caring for ourselves is important for our health and quality of life. It also helps supporters feel better able to meet the needs of people with disability who have experienced trauma. Supporter wellbeing is a shared responsibility. It depends on supporters receiving support from their own family, friends and community. For those people who provide support as a part of their job, it is also a shared responsibility with the service that employs them.

Different supporters have different wellbeing needs. We all need to find what works for us and do those things regularly to help us look after our own wellbeing. Useful wellbeing strategies help in all areas of life, including work and relationships. When providing support to others, it is important to take plenty of breaks when needed. Supporters can get support by speaking with a friend or work colleague or getting formal supervision. It is also helpful to have variety in daily tasks and not do the same thing all day every day. It is important to take time off when sick or tired. Rest and sleep can make a big difference. So does a healthy diet and exercise. Taking time for holidays and family and friends is very important. Socialising and doing fun things can help us all to feel calm and refreshed. It can be helpful to develop a wellness plan that helps you support yourself in lots of different ways. This might include physical, emotional, environmental, professional, social and spiritual ways.

Many people who support people with disability who have experienced trauma may experience burnout, grief or vicarious trauma. Burnout happens when there are too many demands. Burnout can make people feel physically and emotionally exhausted. It is important to notice if you are feeling like this because it is hard to provide support when you feel like this. Feeling this way makes sense when you think about the challenges of providing support. When supporters are feeling burnt out, they might need to take a break or get some extra support themselves. Supporters might find that training or special equipment can make providing support easier. It can help with burnout too.

Practice tip – Managing burnout

Here are some ideas to help you manage burnout:

- Know that it is common and understandable.
- Take breaks if needed and when possible.
- Explore whether specific training or equipment may help.
- Explore whether others can help provide support.
- Check to see if you can reduce your workload or responsibilities.

Sometimes supporters experience grief. Supporters may blame themselves for not being able to prevent trauma. Supporters can feel angry or not want to believe that a person experienced trauma. Sometimes supporters can feel very sad that a person they love has been affected so much by trauma. Supporters may feel sad or resent needing to become a primary caregiver and its impact on their own life and dreams. Supporters can also experience grief as they witness a person's wellbeing decline because of their disability, trauma, aging or poor health. It is important that supporters receive support when feeling this way. Some supporters find it helpful to talk with counsellors or friends about feeling this way.

Practice tip – Dealing with grief

Here are some ideas to help you with grief:

- Notice when you are angry, struggling to believe something or blame yourself for things.
- Know that grief is normal and understandable.
- Know that grief will eventual feel less overwhelming.
- Talk with others about it.
- Think about going to grief counselling.

Vicarious trauma

Vicarious Trauma (VT) is a known risk for anyone who supports people with trauma experiences. This includes caregivers, family, friends, support workers or advocates. VT is a critical Worker Health & Safety (WHS) concern for all services in which workers are exposed to other people's trauma stories and impacts in their jobs.

"Vicarious trauma is the negative transformation in the helper that results [across time] from empathic engagement with trauma survivors and their trauma material, combined with a commitment or responsibility to help them" (Pearlman & Caringi, 2009).

There are lots of different changes you can experience when you experience VT. Some people have a hard time not thinking about a trauma story or person's trauma response. These thoughts might come as flashbacks or nightmares. Sometimes people feel emotionally numb, 'shut down', or dreamlike and dissociative (i.e. hypoaroused). Some people find it hard to relax or sleep (i.e. hyperaroused). Some people may want to avoid other people, places or things that remind them of a person's trauma or a person who has experienced trauma.

Often, people notice that the way they see the world, themselves or others has changed. For example, starting to feel like the world is not safe or that other people cannot be trusted. Or needing more control over other people or themselves. Some people lose hope and feel like trauma is everywhere and cannot be stopped or people cannot recover from it. Some people lose a sense of meaning or purpose in their life. Some people start finding it harder to be empathic or compassionate towards others or need to stop being empathic to protect themselves.

The following case study gives an example of what vicarious trauma could look like for a supporter and how it could come about.

Content warning

This case study contains information that may be upsetting for some people. This is because it talks about violence, abuse, neglect or exploitation of people with disability.

If you have any difficult feelings after reading it, you may want to reach out for support. You may have your own support system you can access.

You can also get support through the Disability Gateway by phoning 1800 643 787 between 8am-8pm Monday to Friday.

Case study - Georgia and Cindy

Georgia was very active in her local community. She volunteered in the canteen at her daughter's school. She coached a local netball team. And she distributed meals to elderly residents with her local church group. One day at church, Georgia met a new person at church. This woman, Cindy had a long trauma history and was paraplegic. Cindy needed support with transport and shopping. She had also recently completed drug rehabilitation. Georgia had struggled with substance use herself in the past. Georgia offered to support Cindy to maintain her sobriety and help with transport and shopping.

Over the next few weeks, Cindy shared her experiences of abuse, neglect and substance use. At times, Georgia felt upset and worried by the trauma Cindy had experienced. Georgia felt more tired and irritable. Sometimes, she thought about Georgia being hurt, or dreamed about the abuse happening to herself. Georgia started to feel less safe or able to trust people like she used to. For the first time in 20 years, Georgia started to think about using alcohol again.

This is not a real person's story.

It is important to be alert to the early warning signs of Vicarious Trauma (VT). They can be hard to see or easy to notice. Anyone exposed to traumatic material or other people's trauma stories is at risk of experiencing VT. Feeling impacted by exposure to trauma material is not a sign of weakness or a fault. In fact, it shows a person's humanity and that you are a caring human being. It is important that supporters, and the services that support them, pick up the early warning signs. When supporters are alert to the early signs, it is easier to pick up that something is wrong. There is a range of strategies to manage the risk and impacts of VT.

Practice tip - Managing vicarious trauma and its impacts

You can start to manage vicarious trauma and its impacts when you notice when you are:

- jumpy, and on high alert
- anxious and cannot relax
- experiencing strong emotions that you cannot manage
- withdrawing and isolating yourself
- feeling helpless and hopeless
- no longer enjoying things you once enjoyed
- feeling as if the world and people are not safe
- questioning your place in the world
- being more cynical or feeling depressed
- having big reactions to violence or abuse (e.g. on television)
- finding it hard to be empathic or compassionate
- struggling with relationships or having a lot of arguments or fights with others
- having trouble sleeping
- misusing substances
- focusing on other people's trauma stories
- not being reliable at work – coming in late, being less productive, not turning up.

Here are some tips to start managing vicarious trauma:

- If possible, reduce your exposure to trauma by reducing the number of people you support, the time you provide support or the type of support you provide.
- Share the load when you can.
- Identify any symptoms early.
- Do something to address the symptoms early.
- Watch your symptoms and notice if they change or when they occur.
- Watch how useful your strategies are at reducing your symptoms.
- Attend to your own needs to support wellbeing regularly.
- Get support for the feelings your role as a caregiver, support worker or advocate bring up - talk about your feelings and responses.
- Reflect on your work - journaling can help you to do this.
- Reach out to trusted friends and colleagues.
- Receive supervision and mentoring from an experienced trauma-informed supervisor.

Preventing abuse and trauma

Everyone has a responsibility to speak out against violence, abuse and neglect when another person cannot do that for themselves. Some abuses might be hard to identify. Like talking about a person's habit or mistake to tease or embarrass that person. Some abuses might be obvious. Like hitting someone or not giving the person treatment to cause them hurt or harm. If you witness abuse or unethical behaviour towards a person with disability, do what you can to stop the abuse. Think about what you can do and who you can ask for help. For more information on how to respond if you witness abuse or unethical behaviour towards a person with disability visit the National Disability Services website at www.nds.org.au/resources/zero-tolerance.

Practice tip - Speak up if something does not look or feel right

If you see something happen or are asked to do something to a person living with disability that does not seem or feel right:

- Try to get the person with disability away from the situation or person that is not safe.
- Try to speak to the people involved about your concern if it is safe to do so.
- Talk to a person you trust about what you saw or heard, such as a supervisor or a friend.
- Call the National Disability Abuse and Neglect Hotline on 1800 880 052 and get advice.
- Consider reporting to police if what you saw or heard was criminal.

Further Information

There is lots of information available to help people learn more about trauma and trauma-informed practice:

Blue Knot Foundation (BKF) has information and training on complex trauma, trauma-informed practice and vicarious trauma available from their website. This includes different guidelines for workers and organisations.

www.professionals/blueknot.org.au/resources

www.professionals.blueknot.org.au/professional-development-training

The NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS) has information about trauma amongst Culturally and Linguistically Diverse (CALD) communities. Information is available on their website:

www.startts.org.au

We Al-Li Pty Ltd has information and training for a Culturally Informed Integrated Healing Approach (CITIHA) for supporting First Nations people to heal from trauma. Further information is available on their website:

www.wealli.com.au

1800RESPECT provides information and support especially for people who have experienced sexual assault or domestic and family violence. You can get this information from their website:

www.1800respect.org.au

National Disability Services (NDS) have information to help build capacity in supporting people with disability. You can get this information from their website:

www.nds.org.au/zero-tolerance-framework/considering-additional-risk

Some organisations also have information for supporting people with specific disabilities. For example, Taking Time is a trauma-informed framework for supporting people with intellectual disability made by Berry Street and funded by the NSW Department of Family and Community Services. You can get this from the Berry Street website:

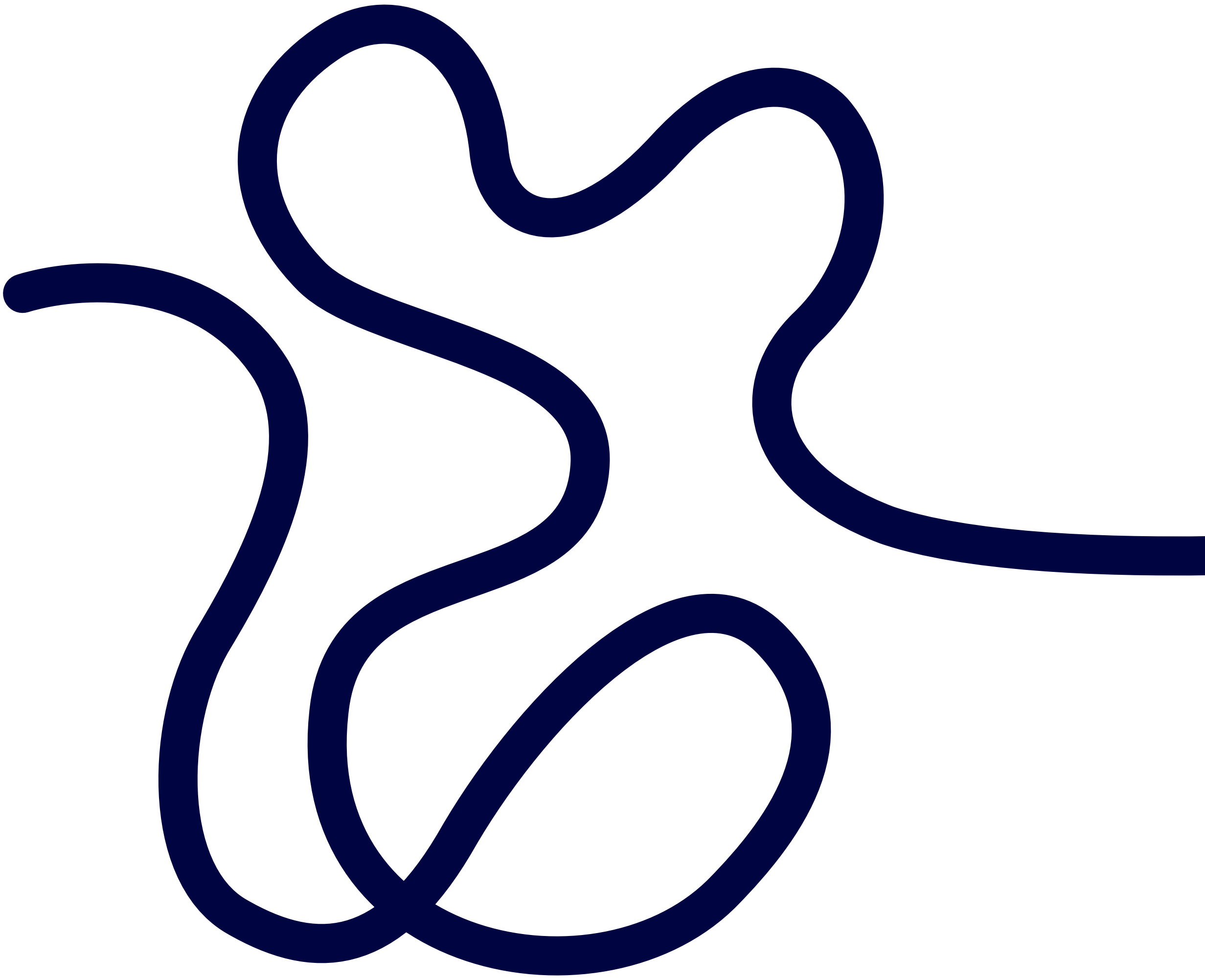
www.learning.berrystreet.org.au/focus-areas/berry-street-education-model

Summary of trauma-informed support for people with disability who have experienced complex trauma

To provide trauma-informed support to people with disability who have experienced trauma, supporters must:

- Understand and uphold the UN Convention on the Rights of Person with Disabilities.
- Follow the Social Disability Model.
- Understand the relationship between disability and trauma.
- Understand trauma and the stress response.
- Understand that complex trauma is repeated, ongoing and extreme trauma.
- Provide culturally sensitive support.
- Notice when a person you are supporting is triggered to be hyperaroused and hypoaroused.
- Understand the relationship between trauma and behaviour labelled as ‘behaviours of concern’.
- Recognise possible signs that someone has experienced complex trauma.
- Support recovery from trauma through providing trauma-informed support.
- Know how to respond to a person when they are telling you about their abuse or trauma for the first time.
- Understand how important it is to try and reduce the risk of a person being re-traumatised.

- Provide support that follows the five-core trauma-informed principles (i.e. safety, trustworthiness, choice, collaboration and empowerment).
- Watch out for burnout, grief and vicarious trauma when providing support.
- Use strategies, such as debriefing, looking after your own wellbeing, and getting supervision to manage burnout, grief and vicarious trauma.
- Act to prevent abuse or trauma.



References

Allman, K. (2015). `The High Cost of Caring', Law Society of NSW Journal (August) pp.38-43.

Australian Bureau of Statistics (ABS:2018). 4430.0 - Survey of Disability, Ageing and Carers.

Australian Bureau of Statistics (ABS:2020). 4715.0 - National Aboriginal and Torres Strait Islander Health Survey, 2018–19, Table 2.1 and Table 2.3.

Australian Government (2020). Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report. Barton, ACT: Attorney-General's Department.

Cozolino, L. (2002). The Neuroscience of Psychotherapy: Building and Rebuilding the Human Brain. New York: Norton.

Hoch, D. & Youssef, A. (2019). Predictors of Trauma Exposure and Trauma Diagnoses for Children with Autism and Developmental Disorders Served in a Community Mental Health Clinic, Journal of Autism Developmental Disorders, 50(2), pp. 634–649. Published online 2019 Dec 14. doi: 10.1007/s10803-019-04331-3

Kezelman, C.A. & Stavropoulos, P.A. (2012). The Last Frontier: Practice Guidelines for Treatment of Complex Trauma and Trauma-Informed Care and Service Delivery. Sydney, Blue Knot Foundation, 2012. www.professionals.blueknot.org.au/resources/publications/practice-guidelines

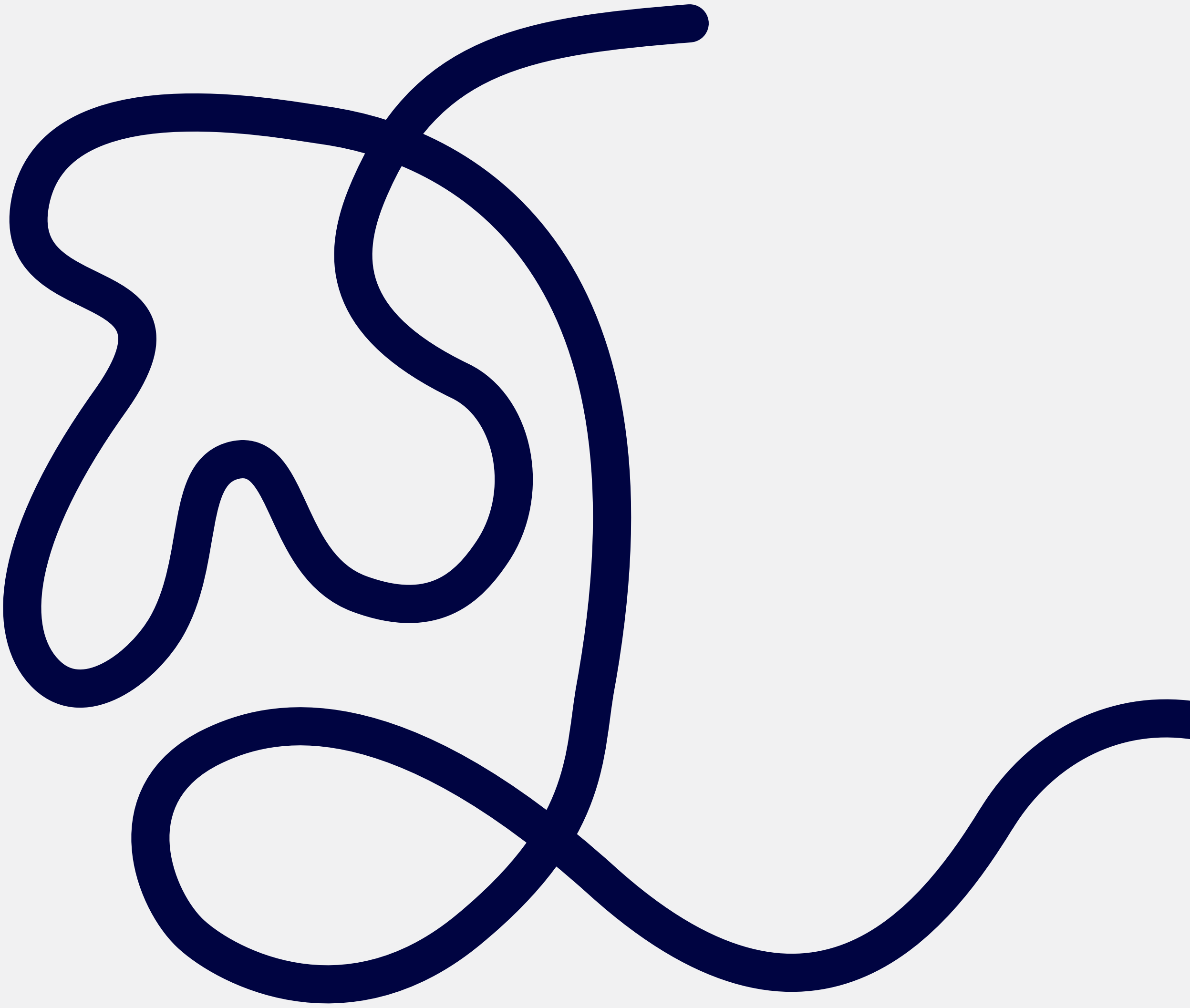
Lowitja Consulting (2018). Journeys to Healing and Strong Wellbeing Final Report. Carlton South, VIC: Lowitja Consulting.

Pearlman, L.A. & Caringi, J. (2009). Living and Working Self-Reflectively to Address Vicarious Trauma', ch.10 in Courtois, C. A. & Ford, J. D. (eds.) Treating Complex Traumatic Stress Disorders. New York: The Guilford Press, pp.202-224.

Royal College of Psychiatrists (2007). Challenging Behaviour: a unified approach. Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr144.pdf?sfvrsn=73e437e8_2

Sutherland, G., Kavanagh, A., Llewellyn, G., Byars, S., Krnjacki, L. and Hargrave, J. (2020). Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, March 2020, p 7.

Van der Hart, O., Nijenhuis, E. R. & Steele, K. (2006) The Haunted Self: Structural Dissociation and the Treatment of Chronic Traumatization. New York: Norton.



Language and Terms

We have tried to write this guide in simple and easy-to-understand language. This is so as many people as possible can read the guide. This document complies with Web Content Accessibility Guidelines. The following terms are used in this guide:

Advocates are people who act, speak or write to support a person with a specific issue. Advocates are usually employed by an independent advocacy organisation to reduce any conflicts of interest. Advocates may have specific qualifications or training.

Burnout is caused by feeling overwhelmed when you are not able to meet constant demands. It is the emotional, physical and mental exhaustion that comes from long-term stress.

Caregivers are often family members or friends who provide a range of care, assistance and support to people with disability. They are often unpaid. Caregivers may assist with a range of needs, including personal care, transport, communication and social support.

Collaboration means working together and doing something 'with' a person rather than doing something 'for' or 'to' the person.

Complex trauma is repeated and ongoing trauma. It builds up and happens when one or more people seriously harm and cause trauma to another person. When trauma starts early in childhood it can cause a lot of damage. The impacts can be lifelong and affect people in many areas of life.

Confidentiality is not sharing personal information about a person unless the person consents or says it is okay to provide that information to someone else.

Deaf (with a capital D) is used to refer to those who use sign language such as Auslan and identify culturally as members of the signing Deaf community.

deaf (with a lower case d) is a broader term than Deaf (with a capital D). It is used to describe people who are physically deaf or the physical condition of not hearing but do not identify as members of the signing Deaf community.

Debrief (in this context) is when you talk through with a trusted person about how you are feeling about something that happened.

Disability is the result of the interaction between a person with impairment(s) and attitudinal, environmental or social barriers that compromise full, equal and effective participation in society.

Dissociation is the separation of brain and body functions that generally work together. These include thoughts, feelings, body sensations and behaviours. Severe dissociation is usually caused by trauma. When we dissociate because of trauma we cannot function in a smooth integrated or coordinated way. These splits or divisions in our key functions happen outside of our conscious awareness.

Empathy is the ability to understand and feel what another person is feeling (Bellet & Maloney, 1991). It is different to sympathy. Sympathy is more like feeling sorry for someone. Empathy has two parts - understanding the feeling and feeling the feeling. Sometimes people can also feel another person's physical reaction, like feeling sick in the stomach or tense in the head.

Empowerment is the process of gaining more control in your own life and claiming your rights. It is about becoming stronger and more confident.

First Nations people is the phrase used in this guide to reference Aboriginal and Torres Strait Islander people. This is consistent with the language used by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. However, it is recognised that the terms First Peoples of Australia and First Australians are also increasingly commonly used. It is also recognised that in situations in which a person's specific cultural group or mob is known, reference to the specific cultural group is preferred.

Flashbacks are the sudden and unexpected reliving of trauma memories. They often come with strong feelings including terror and distress. They can also come with strong sensations and body movements. Flashbacks occur when we are reminded of traumatic events and past experiences take over so that it can feel as though they are happening in the present.

Impairment is a condition or personal attribute. For example, a cognitive impairment might relate to a condition or attribute that affects memory, spatial awareness or planning. It is not the same as a cognitive disability, which occurs when cognitive impairments interact with attitudinal, environment and/or social barriers and prevent full and equal participation in society.

Hyperarousal is when you feel agitated, edgy, jumpy and unable to settle after being triggered or reminded of a traumatic event.

Hypoarousal is when you feel numb, shut down, 'zoned out' or on autopilot after being triggered or reminded of a traumatic event.

Person with Disability is the person-first language used in this guide to refer to people with disability. This is intended to convey respect and acknowledgement to not unnecessarily focus on a person's disability. However, it is recognised that this phrase does not fully capture all the unique differences within living with disability. It is also recognised that some people prefer identity-first language. For example, deaf person or autistic person.

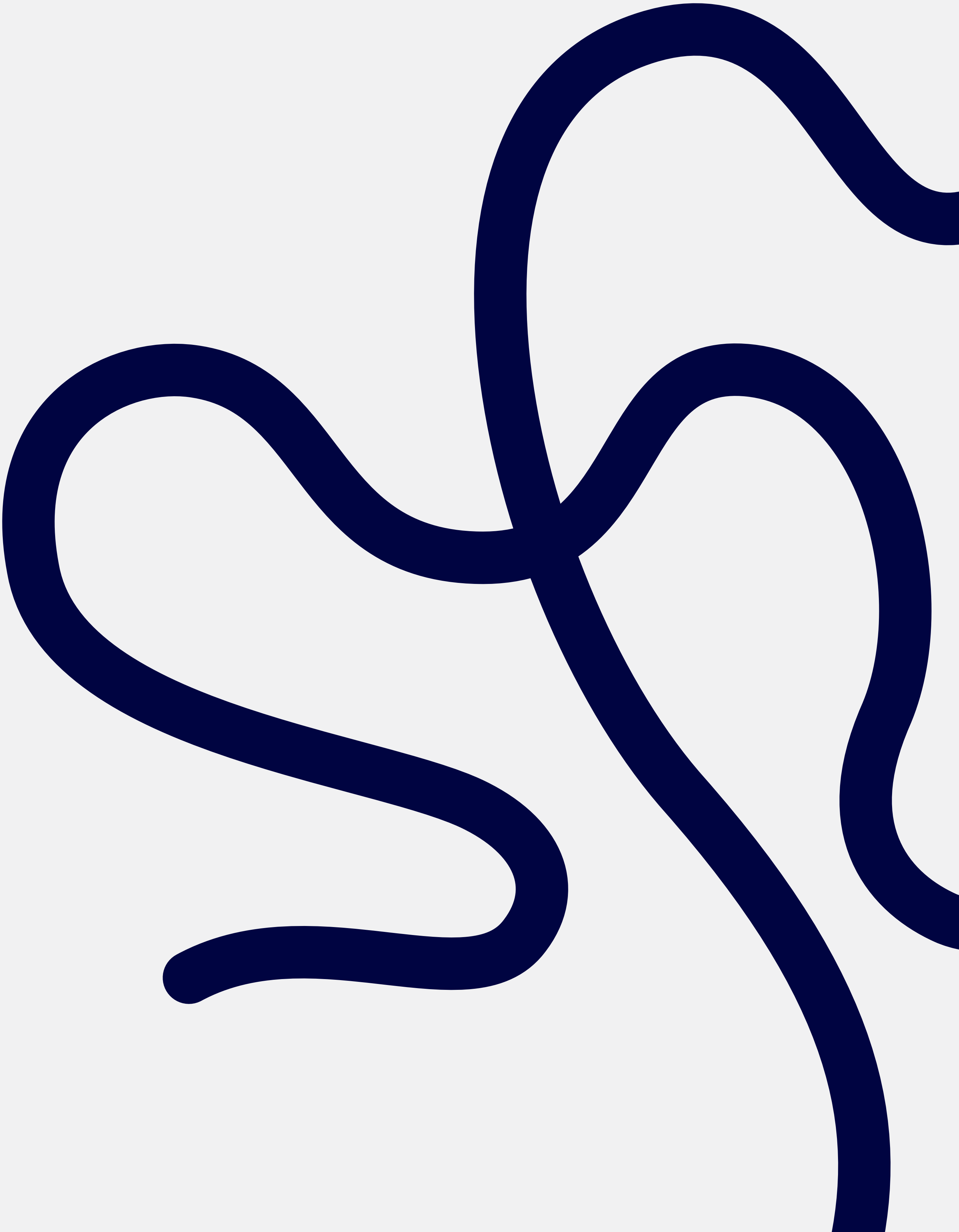
Re-enactments are the same as flashbacks and are sudden and unexpected reliving of trauma memories. They often come with strong feelings and bodily sensations and can feel as though a traumatic event is happening again. We start to behave like we did during the traumatic event.

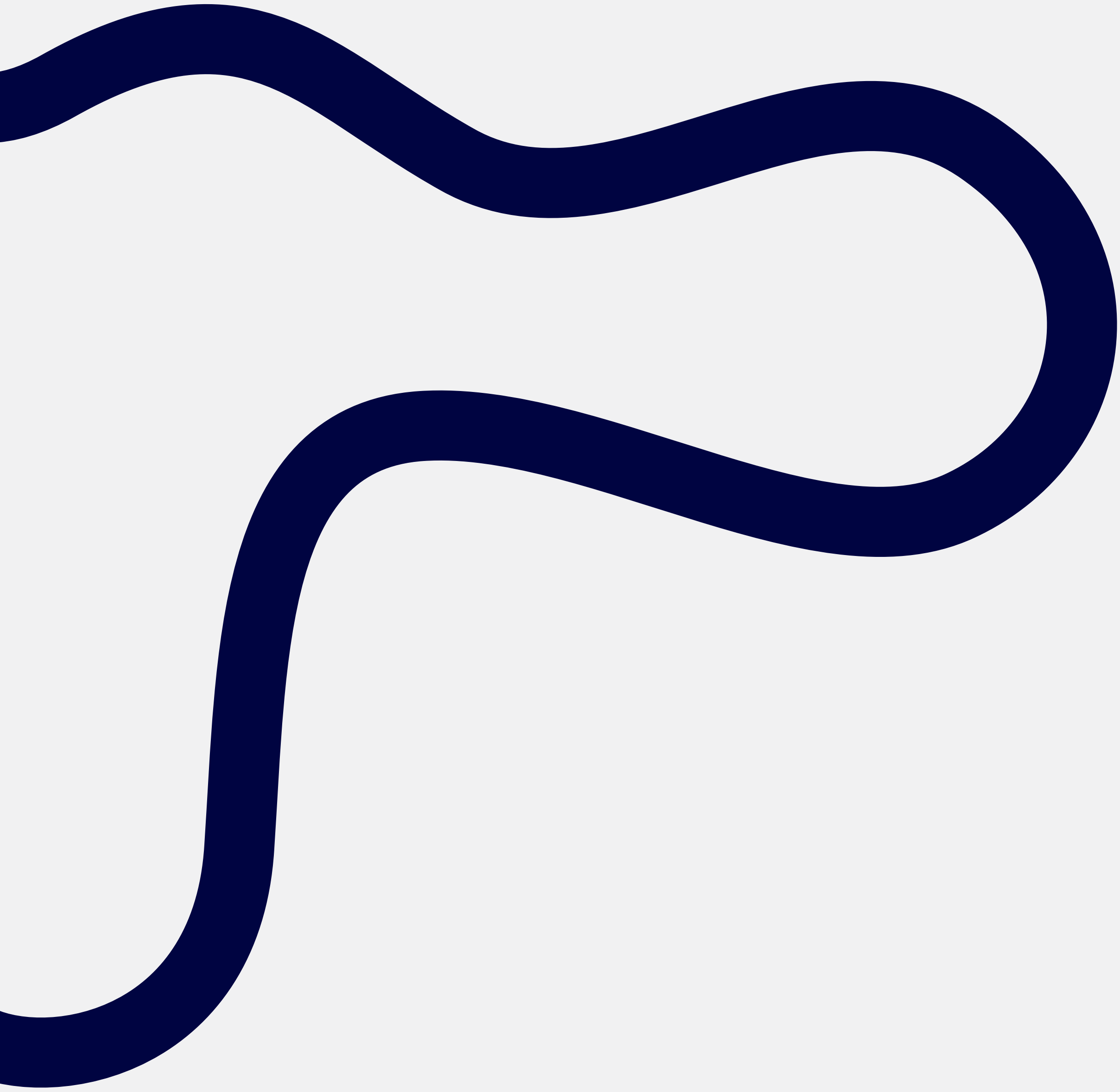
Supervision (in this context) is when someone more experienced than you helps guide and support you to provide the best support possible.

Support workers are contracted as paid or voluntary workers. They provide a range of assistance and support to people with disability. Support workers may not have any formal qualifications or training. They may be employed by an organisation or service or directly by the person with disability. Support workers may assist with a range of needs, including personal care, transport, communication and social support.

Supporters is the term used in this guide to refer collectively to anyone who provides support to a person with disability. This may include a caregiver, support worker or advocate.

Vicarious trauma is when you start to feel the impacts of trauma because of your empathic engagement with people who have experienced trauma and hearing or witnessing their trauma stories. It typically involves changes in the way you view yourself and the world and brings a sense of hopelessness or loss of meaning.





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empowering recovery from complex trauma