

**Exploring Risk**

A Zero Tolerance Research Report

# Exploring Risk:

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## Foreword

Abuse, neglect, exploitation and violence towards people with disability are unacceptable violations of human rights. Despite this there is considerable evidence that people with disability continue to be at greater risk of neglect, abuse and violence than people without disability.

The introduction of the National Disability Insurance Scheme (NDIS) presents new opportunities for people with disability to have more choice and control over their lives and the supports they use. However, transition to the NDIS also raises new challenges to ensuring people with disability are safe from abuse as people seek more supports in their homes and the wider community.

The disability sector and wider community have a responsibility to ensure that people with disability can live their lives safely. This is articulated in the *National Disability Strategy 2010-2010* and underpins the new Quality and Safeguarding Framework for the NDIS.

Cognisant of the need to improve safeguarding knowledge and capacity in the disability sector, NDS has used its unique position to undertake collaborative research with statutory bodies, expert professionals, academics, advocacy organisations and service providers to develop the *Zero Tolerance* *Initiative*.

*Zero Tolerance* provides guidance for providers of disability services across Australia on the range of actions required to prevent abuse and improve responses for victims. It offers a curriculum of safeguarding topics for CEOs, boards, senior managers and frontline staff to address as part of their safeguarding approaches.

*Zero Tolerance* has a universal approach which acknowledges that abuse and neglect is a complex societal problem. Drawing from established violence prevention models it builds on a human rights platform to set out a range of actions that, when enacted fully, will reduce risk of abuse, neglect and violence.

However, universal approaches alone may not be adequate to ensure the safety of all people with disability. Factors unique to specific cohorts of people with disability, or features of specific service environments may, alone or in combination with each other, pose additional risks. In commissioning this report NDS hoped to identify risks that might require targeted approaches and in doing so be able to guide the development of future work.

NDS would like to express our gratitude for the time and expertise provided by individuals and organisations in the development of the *Zero Tolerance* resources and more specifically those who helped inform this report. It is only through such collaborations that we can achieve our aim of eliminating abuse and violence and ensuring people with disability can live as equals in society.

David Moody

State Manager, NDS Victoria

**April 2017**

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**About the Authors**

The Nucleus Consulting Group provides consulting, evaluation and research services to government, business and community organizations, specialising across a wide range of services types, and in particular disability support.

Nucleus has successfully completed a number of projects reviewing and developing effective ways to safeguard rights, maintain quality of service and minimise risks to people with disability. Nucleus strives to contribute to solutions through the introduction of positive and practical advances - in particular, our consultants all have deep experience in service delivery, combining knowledge of contemporary research with an understanding of how this is best translated into practice.

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For more information and resources from the *Zero Tolerance Initiative* please visit: <https://www.nds.org.au/resources/zero-tolerance>

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## **Introduction**

Recent years have seen a significant increase in public discourse on the safety of people with disability. A number of high profile statutory, parliamentary and advocacy led consultations and reports focused on the prevalence, causes and responses to abuse, violence and harm experienced by people with a disability across Australian society.

Although each took a different focus, a clear picture emerged: people with disability are at higher risk of abuse and violence than people who do not have disability.[1](#_ENREF_1), [2](#_ENREF_2) This is widespread and may occur where people live, work or recreate. It can involve multiple incidents, be severe in impact, sustained over time and may involve people close to the individual.

Findings showed that abuse, violence and neglect of people with disability may be intentional and criminal but also may arise from attitudinal, systemic and environmental barriers that impinge upon an individual’s human rights and freedoms. The Senate Community References Committee,[3](#_ENREF_3) reporting in November 2015, concluded that a de-valuing of people with disability is a root cause of abuse, violence and neglect, calling for a Royal Commission into the issue.

Peer reviewed literature and the many submissions made to these national and state parliamentary inquiries all clearly articulate concerns about the legislative, policy and service frameworks intended to ensure people with disability are free from abuse, violence and neglect. At the heart of this is how disability is conceptualised and understood with recognition that “attitudinal and environmental barriers hinder…full and effective participation in society on an equal basis with others”.[1](#_ENREF_1) System and community level changes are identified as key safeguarding requirements in the pursuit of “creating safe spaces, cultures, environments……. in which people’s voice[s] [are] heard and respected”. [5](#_ENREF_5)

A number of important steps have been taken over the past decade to understand, prevent and address abuse, violence and neglect of people with disability. Key foundational principles to improve safeguards have been identified and articulated by organizations and bodies in pockets across Australia. Drawing on these principles and contemporary thinking, National Disability Services (NDS) has developed the *Zero Tolerance* initiative.

Framing abuse within a universal human rights framework, where all people have the right to an acceptable standard of living and protection against exploitation, violence and abuse, *Zero Tolerance* seeks to identify best practice in universal safeguarding approaches and violence prevention and translate them via accessible, practical tools and resources for the disability sector.

Building on the significant work already undertaken, this report furthers the work of the *Zero Tolerance* initiative, focusing on the nature of risk for specific cohorts of people with disability and understanding service features and settings that increase risk. It seeks to identify useful existing work and products that should be promoted and adopted, as well as any gaps that might be addressed through policy, practice and research.

## Purpose

The *Zero Tolerance* initiative and framework have a universal approach. They assume all people have human rights and set out approaches whereby people with disability are able to enjoy those rights in a safe way when using disability services. [99](#_ENREF_99)

The *Zero Tolerance* Expert Reference Group identified groups or ‘cohorts’ of people with disability who may be at additional risk of harm. These included:

* people with intellectual disability
* people with complex communication support needs
* women with disability
* children with disability
* people from indigenous or culturally and linguistically diverse communities
* people with acquired brain injury
* Deaf people or those with a hearing impairment
* people with disability with no informal support networks
* people with disability at risk of familial abuse[[1]](#footnote-1)

Various ‘service settings’ – the places where people receive their disability supports – were also identified as posing potential risks that universal approaches might not sufficiently address. These include:

* institutions and congregate accommodation settings
* group homes
* supported employment and day services
* centre-based and in-home respite services
* community-based one-to-one supports.

The purpose of this report is to explore whether the nature of risk for these cohorts and services settings are well understood and considered in contemporary approaches to safeguarding the rights of people with disability.

It considers if the universal approaches, such as those set out in the *Zero Tolerance* Framework are sufficient to address risk of harm for all people with disability who use disability services and if not what additional supports might be identified and implemented.

The report also aims to identify any useful existing research or work that can improve understanding and strengthen policy and operational approaches by the Department of Health and Human Services and service providers, and make recommendations to the Department of Health and Human Services on possible future work to address knowledge and practice gaps.

## Approach

Through development of the *Zero Tolerance* Framework, NDS was aware of the significant existing work undertaken by academics, advocacy groups, government and statutory bodies to increase understanding of abuse and neglect experienced by people with disability. Parallel inquiries by the Australian Senate Community Affairs References Committee, the Victorian Parliament, the Victorian Ombudsman as well as submissions made to the Australian Government Department of Social Services regarding the NDIS Quality and Safeguarding Framework saw much drawing together of existing research and literature, including grey literature. As a result NDS was able to develop a comprehensive list of literature for review in preparing this report. This was augmented by additional high-relevance resources identified during the review.

Expert advisory committees from the disability sector were assembled to assist in guiding this work and identifying any gaps. These included representatives from:

* The Office of the Disability Services Commissioner
* The Office of the Public Advocate
* Victorian Advocacy League for Individuals with Disability (VALID)
* Association for Children with Disability (ACD)
* Women with Disabilities Victoria (WDV)
* Scope Communication and Inclusion Resource Centre (CIRC).

Input was also sought from the NDS Victoria *Zero Tolerance* *Safeguarding Reference Group* comprising the following volunteers from Victorian disability service providers:

* Elizabeth Bingham – Workforce Analyst, EACH
* Lisa Cook – Senior manager, Catholicare
* Jantine Eddelbuttel – General Manager Human Resources, E. W. Tipping
* Lynda Galt - Executive Manager Operational Support, ONCALL Personnel and Training
* Keith Hitchen, Executive Officer, Action on Disability within Ethnic Communities (ADEC)
* Rebecca Hogea – Manager Clinical Services, LifeAssist
* Kim Kavanagh - Program Manager - Individual Services, Vicdeaf
* Naomi Rezzani - Communication & Inclusion Resource Centre, Scope
* Amy Padgham – Operations Manager, Multiple Sclerosis Limited
* Karen Robinson - CEO, Karden

## Understanding Risk

Research shows that people with disability are at greater risk of abuse, violence and neglect. Risk is a threat or hazard which cannot be predicted to occur with certainty.[13](#_ENREF_13) Abuse is the violation of a person’s human or civil rights and may include physical, sexual and psychological or emotional abuse.

### Positive approach to risk-taking

Risk can be understood through two lenses:

* Firstly, from a human rights framework - that all people have the right to an adequate standard of living and protection against all forms of exploitation, violence and abuse[16](#_ENREF_16), [21](#_ENREF_21), [25](#_ENREF_25)
* Secondly, from a strengths-based approach for dealing with risk rather than over-protection. This means recognising that risk-taking may have positive as well as negative outcomes.[13](#_ENREF_13), [16](#_ENREF_16)

A balance needs to be found between safeguarding someone from harm and enabling someone to live more independently through effectively managing risks themselves.[16](#_ENREF_16) Some refer to the ‘dignity of risk’ or the right of people with disability to make an informed choice to experience life and take advantage of opportunities for learning, developing competencies and independence through taking calculated risks.[13](#_ENREF_13), [16](#_ENREF_16), [25](#_ENREF_25)

### ‘Intersectionality’

Research shows that people with disability are at greater risk of multiple and intersecting forms of abuse, harm and neglect due to a range of factors. On their own, some of these factors may seem insignificant, but when combined they may give rise to or create conditions leading to abuse.[18](#_ENREF_18)

The nature of risk can be different for different cohorts of people and may be multiplied by ‘intersectionality’, the compounding effect of multiple and intersecting layers of discrimination based upon such characteristics as gender and diversity. For example, violence has been found to intensify in frequency, extent and nature when gender and disability intersect.[19](#_ENREF_19)

Discrimination affects people in very different ways – as various elements (e.g. gender, ethnicity, race, location) overlap or intersect to produce different risks and experiences of violence.[20](#_ENREF_20) Intersectionality suggests that particular groups (including for example, those based upon religion, race, culture, ability, sexual and gender identity, refugee status) are at higher risk and experience multiple forms of violence and abuse.[20](#_ENREF_20), [21](#_ENREF_21) The experience of abuse of people with disability is often shaped by other dimensions of their identities, such as race, ethnicity, gender or class.[22](#_ENREF_22)

The concept of intersectionality may be extended to include compounding effects related to the service setting. Abuse, violence and neglect of people with disability may be intentional and criminal but also may arise from living in shared housing, poor planning or service management, power disparities and attitudinal, systemic or environmental barriers relating to where a service is delivered.

Understanding intersectionality is important in grasping the fabric of people’s lives. It is suggested that intersectional discrimination has unique and specific impacts on people with disability, and may lead to other forms of discrimination, some not acknowledged by law, policy or in research.[20](#_ENREF_20) [21](#_ENREF_21) In particular, researchers believe that the gendered violence experiences of women and girls with disability have been unrecognised in the broader policy approaches to the prevention of violence against women.[20](#_ENREF_20) It is suggested that understanding intersectional discrimination is critical to conceptualising disability and human rights violations of people with disability[21](#_ENREF_21) and in the development of disability policy and service provision frameworks.[20](#_ENREF_20)

## The Evidence Base

### Adequacy of the Evidence

The evidence base to help understand the extent and type of abuse experienced by different cohorts, where it takes place and effective responses is not strong.[1](#_ENREF_1) Peak bodies, advocacy groups, researchers and government bodies agree that the current evidence base is unsatisfactory and offers little to inform policy direction and service design.[3](#_ENREF_3), [26](#_ENREF_26), [27](#_ENREF_27) This is the case internationally as well as in Australia.[1-3](#_ENREF_1) A strong evidence base is important because it is critical in understanding risk and protective factors and developing interventions that might prevent violence.[1](#_ENREF_1)

Data collection regarding the prevalence and incidence of abuse, violence and neglect against people with disability is limited, scattered,[21](#_ENREF_21) narrow in scope (not specific to particular impairment types),[26](#_ENREF_26) siloed in government departments or not generally available.[28](#_ENREF_28)

Further, the data that is collected may not give a true picture of the extent of violence, abuse or neglect experienced by people with disability for the following reasons:

* Data that is collected is not consistently defined or captured across Australian states and territories. For example, the current data mostly does not include (or captures poorly) information on the nature of disability, types of violence, abuse and neglect experienced, how widespread, how often or where it occurs[3](#_ENREF_3)
  + National data collections such as the Australian Bureau of Statistics’ Personal Safety Survey, the General Social Survey and the Disability, Ageing and Carers Survey may systematically exclude people living in remote areas, people living in institutional settings and people with communication support needs[3](#_ENREF_3)
  + The true incidence of abuse is likely to be under reported, given a wide range of barriers to reporting.[4](#_ENREF_4), [21](#_ENREF_21) Examples include:
    - * The closed nature of many residential settings, and organisational cultures oriented towards ‘covering up’[29](#_ENREF_29)
      * Fear of not being believed or of self-reports being discounted[32](#_ENREF_32)
      * Dependence of persons with disability on their carers/service providers and fear of retribution or service withdrawal[96](#_ENREF_96)
      * Fear of retaliation against whistle-blowers[31](#_ENREF_31)
      * Lack of awareness, education and training for persons with disability and support workers[30](#_ENREF_30)
      * Various forms of abuse of people with disability are not seen or understood as such, as under certain specific circumstances they are condoned under current laws, systems or policies (for example, restrictive practices).[21](#_ENREF_21)

There are also other problems with the evidence-base, including:

* Many research studies are small and use weak research methods[1](#_ENREF_1), [26](#_ENREF_26)
* There are gaps in evidence (e.g. there is little on abuse, violence and neglect of people with sensory disabilities[1](#_ENREF_1) or of people who use augmented communications)[34](#_ENREF_34)
* Definitions of abuse, violence and neglect used as the basis for research may vary[33, 96](#_ENREF_33) (and should be contemporised to include, for example, financial exploitation in packaged funding arrangements).

### A Whole of Issue Perspective

A key finding from this review is the need for a holistic understanding of abuse and responses to it. Issues around abuse, violence and neglect are multi-layered and highly complex, not easily resolved and reliant upon shifts occurring in the broader community, service delivery systems and at individual levels. These include shifts to address attitudinal, cultural and environmental barriers experienced by people with disability.

To build safeguarding capacity within communities, organisations and service settings, a holistic understanding of abuse and potential responses is required:

|  |  |
| --- | --- |
| A complex social problem | * The interaction of relationships, environment and culture are core factors in the occurrence of abuse[1](#_ENREF_1), [27](#_ENREF_27) * A social relations approach to disability locates the ‘problem’ of disability in the environment and not in the individual. Its action implication is environmental change[4](#_ENREF_4) |
| De-valuing of people with disability | * Is a major cause of violence, abuse and neglect of people with disability and affects the attitudes of individual disability workers, service delivery organisations and government systems designed to protect the rights of individuals[3](#_ENREF_3) * Attitudes that de-value people with disability shape individual carer behaviours as well as institutional patterns and contribute to institutional barriers to eliminating abuse and violence [3](#_ENREF_3) |
| Intersectionality | * People have multiple sets of relationships and intersecting layers of discrimination (such as gender, sexuality, ethnicity, cultural)[21](#_ENREF_21) * Interactions between specialist and mainstream systems (including health, disability, child protection, education, domestic violence, family and social support systems) need to be re-framed[1](#_ENREF_1) |
| Influence of broader social/systemic factors | * Concurrent impacts caused by, for example, poverty,[33](#_ENREF_33) exclusion from education and employment, communication barriers,[1](#_ENREF_1) inadequate housing, exposure to domestic violence, and poor quality health care[35](#_ENREF_35) * Dependency upon services/support leaving individuals left with little recourse to address their concerns[36](#_ENREF_36) * Negative traditional beliefs and ignorance within communities.[2](#_ENREF_2) |

### 

### A Conceptual Model

The literature describes several variations of multi-level models of protective and preventive actions and strategies as ways to minimise abuse, violence and neglect. A second, small stream of literature covers the development of interventions, strategies and programs to prevent and mitigate the consequences of abuse, violence and neglect against persons with disability (although evaluation of the effectiveness of such strategies and programs is not complete).[26](#_ENREF_26), [94](#_ENREF_94)

The literature appears to be in agreement that conceptual models based upon several different levels of intervention have potential to impact both prevention and intervention. Drawing upon work undertaken by the World Health Organisation that proposes a public health approach towards prevention of violence,[26](#_ENREF_26), [39](#_ENREF_39), [95](#_ENREF_95) [96](#_ENREF_96) a multi-level model recognises the need for a multi-layered, multi-strategy approach to a complex problem. In particular, this may involve advocating community level responses, responses targeting high-risk of harm groups and resources to support and aid recovery for those who have experienced harm.[5](#_ENREF_5)

Elsewhere, commonly, three levels of intervention are described: [27](#_ENREF_27), [39](#_ENREF_39), [97](#_ENREF_97), [98](#_ENREF_98)

* Primary interventions – to prevent abuse occurring in the first instance
* Secondary interventions – to identify and respond directly to disclosures of abuse
* Tertiary interventions - to remedy any negative and harmful consequences and to put in place measures to prevent re-occurrences.

Mikton and Shakespeare (2014)[33](#_ENREF_33) suggest that to effectively address violence against persons with disability at the population level, four key steps need to be achieved:

* Defining the problem and its consequences conceptually and numerically
* Investigating why the problem occurs by determining its risk and protective factors and causes and the factors that might be modifiable through intervention
* Devising ways to prevent the problem by using the above information and designing, monitoring and assessing the effectiveness of programs through outcome evaluations
* Scaling up effective interventions, disseminating knowledge about them, and assessing their cost and cost-effectiveness.

The literature underlines the need for a consistent framework within the sector to reduce the risk of people with disability being subjected to abuse, harm and neglect. Such a framework would:

* Prioritise and target prevention[26](#_ENREF_26), [33](#_ENREF_33), [37](#_ENREF_37)and address early warning signs (such as reducing isolation), recognising ways in which people may express their experiences[38](#_ENREF_38)
* Strengthen individual capability through empowerment, information and choice[25](#_ENREF_25) [16](#_ENREF_16), [39](#_ENREF_39)
* Appropriately respond to individual incidences of harm that occur [27](#_ENREF_27)
* Balance choice and independence with responses that seek to achieve personal safety through over-protection or having control unnecessarily placed with others [27](#_ENREF_27)
* Work across sectors to tackle the causes of abuse rather than just the symptoms.[36](#_ENREF_36)

The NDS *Zero Tolerance Framework* (see Appendix A) unites and integrates these various approaches to incorporate five tiers as guide to the development of tools and resources to help organisations improve safeguards for the people they support:

* Understanding abuse
* Practices and safeguards which can help prevent abuse (primary prevention)
* Risk factors for specific groups and service settings (targeted prevention)
* Responding to abuse (secondary prevention)
* Analysis, learning and improvement (tertiary prevention).

### Cohorts of People with Disability

Research which informed the *Zero Tolerance Framework* suggested that certain groups of people with disability may be at additional risk of harm. These groups include:

* people with intellectual disability
* people with complex communication support needs
* women with disability
* children with disability
* people from indigenous or culturally and linguistically diverse communities
* people with acquired brain injury
* Deaf people or those with a hearing impairment
* people with disability with no informal support networks
* people with disability at risk of familial abuse.

In broad terms, the evidence base generally affirms this, however much of the literature focuses upon people with intellectual disability, with more limited focus on abuse experienced by people with communication or sensory impairments, those with high support or behavioural support needs, and those from Indigenous or culturally or linguistically diverse (CALD) backgrounds. There is relatively little or no work dissecting the characteristics that might increase risk for other cohorts of people with disability, including people with an acquired brain injury or older people with disability.

Notable findings include that:

* Women of all ages and disabilities are at higher risk of abuse, violence and neglect[19-21](#_ENREF_19), [40](#_ENREF_40)
* Children and young people with disability experience abuse and neglect at rates higher than children who do not have disability[27](#_ENREF_27) [41](#_ENREF_41)
* Children with speech/language impairments are more at risk of neglect and abuse than children without disabilities[41](#_ENREF_41)
* Aboriginal and Torres Strait Islander people with disability[3](#_ENREF_3), [21](#_ENREF_21) and people with disability from CALD backgrounds[42](#_ENREF_42) face higher risk of abuse and violence
* People with mental illness are more at risk of abuse than non-disabled adults[1](#_ENREF_1)
* Older people (especially women, and, those in rural/remote locations) experience additional barriers to safety[44](#_ENREF_44)
* Men with disabilities are more likely than women with disabilities to experience physical violence, while women are more likely to experience sexual violence, partner violence and stalking and harassment.[46](#_ENREF_46)

The following tables provide further detail of the risks of abuse faced by specific cohorts of people with disability (gathered from available literature, noting limitations in a number of areas):

| **People with intellectual disability** | |
| --- | --- |
| What the literature says | People with intellectual disability (both male and female) are more likely to experience abuse (physical, sexual) than the general population.[1](#_ENREF_1), [8](#_ENREF_8), [9](#_ENREF_9) Research reports that people with intellectual disability are:   * 1.6 times more at risk than non-disabled individuals of having experienced violence in the past year. The risk tripled when a mental health condition was also present[9](#_ENREF_9) * Experience an annual prevalence rate of violence (sexual, physical, intimate partner violence) of 6.1%[9](#_ENREF_9) * Experience the highest lifetime prevalence rate of maltreatment (physical abuse, sexual abuse, verbal and psychological or emotional abuse, neglect and financial exploitation)[17](#_ENREF_17) * Ten times more likely to experience violence than people without disability[23](#_ENREF_23) * 50-99% are subject to sexual assault at some point in their lifetime[10](#_ENREF_10), [15](#_ENREF_15), [23](#_ENREF_23), [24](#_ENREF_24)   A consistent finding in the literature is that people with intellectual disability (in particular with high support needs and behaviours of concern) are much more likely to experience abuse (physical, sexual, financial, emotional) than the general population.[8](#_ENREF_8) Service user behaviours of concern have been associated with an increased risk of physical assaults by staff, use of physical restraints, or harm inflicted as a consequence of inappropriate or ill equipped responses by staff[8](#_ENREF_8)  The nature of support provided by services may increase risk of abuse for people with intellectual disability. Tasks that may make a service user at higher risk to abuse include such things as providing personal and intimate care[19](#_ENREF_19), [20](#_ENREF_20) and assistance with money management.[18](#_ENREF_18), [21](#_ENREF_21) Particular risk is associated with abuse becoming part of the support process (for example, restrictive practices or over-medication) and thus unrecognised[8](#_ENREF_8)  Women with intellectual disabilities are at a considerably heightened risk of experiencing sexual assault compared with other women with disabilities.[3](#_ENREF_3) Perpetrators who seek out partners they see as submissive, easily controlled, or in some way ‘deserving of abuse’ because of their disability, target women who are least able to resist or make a formal complaint[8](#_ENREF_8)  Most commonly, perpetrators of sexual abuse against people with intellectual disability were men (between 93-100%).[27](#_ENREF_27) [15](#_ENREF_15) [22](#_ENREF_22) A UK study of abuse of people with intellectual disability found that perpetrators were more likely to be fellow residents (in 61% of confirmed cases).[27](#_ENREF_27) Another UK study found that perpetrators of abuse of people with intellectual disability (in residential care) were staff or managers (46%), other service users (26%), or family/partner/carers (23%)[15](#_ENREF_15)  How acts of violence are dealt with influences future risk exposure for people with intellectual disability. For example, when acts of violence are not responded to appropriately, further violence is likely to be perpetrated against the person and it is also less likely that the person will report it[22](#_ENREF_22)  As service delivery models shift towards individualised funding packages, several recent papers suggest risk may increase for people with intellectual disability who are socially isolated, have significant care needs or are receiving services from carers working alone or remotely supervised [17](#_ENREF_17), [18](#_ENREF_18) |
| Knowledge gaps | Multiple recent reports covering the provision of support services[1-5](#_ENREF_1) to people with intellectual disability have noted the inability of the system to make any lasting reforms on the ongoing and high levels of abuse, neglect and exploitation experienced by this group, calling for effective and urgent reform of the current system  There are large gaps in knowledge regarding a ‘true-picture’ of the prevalence and incidence of abuse, violence and neglect specific to people with intellectual disability - in particular, how often and what types of abuse occur (ie sexual, physical, emotional, financial, gendered). Research that seeks to accurately capture and reflect the extent of abuse (in all various forms) and increase the detail of information about incidents (including type, location, perpetrators) will allow development of a strong evidence base that is critical to understanding risk and protective factors and developing interventions that might prevent violence  The full extent of the level of risk and prevalence of abuse faced by people with intellectual disability is also limited and constrained by obstacles to disclosing abuse such as fear of losing services, not being believed, dependence upon others for support, communication difficulties and a lack of awareness of rights and what constitutes abuse.[8](#_ENREF_8) Little is known about the factors that lead to under-reporting or non-disclosure of incidents and effective strategies to increase reporting  Knowledge gaps exist with respect to effective interventions regarding perpetrator behaviours as well as into the features of organisational cultures that support abuse and strategies to achieve lasting change  Some limited examples exist but there is a need to invest further in research into evidence-based outcomes of interventions and practice guidelines to prevent and respond to incidents of abuse, violence and neglect against persons with intellectual disability. In addition, research is needed to examine how to evaluate preventative programs and intervention costs or benefits[24](#_ENREF_24), [28](#_ENREF_28) |
| **People with complex communication support needs** | | |
| What the literature says | People who use augmentative and alternative communication (AAC) rely upon a communication system such as signing, a communication display or voice output device to supplement or replace speech or writing. This may include individuals who have complex communication needs because of a congenital physical disability, an acquired disability or intellectual disability. Many may require assistance a verbal partner to encode the message/ensure the listener understands the message correctly.[30](#_ENREF_30) Difficulties in communication affect one in seven users of disability services over the age of five who have little to no functional speech and over 40% require communication assistance.[29](#_ENREF_29) People with complex and multiple disabilities and those who are non-verbal are particularly at risk, require additional safeguards and support and may be less able to communicate instances of abuse or neglect[17](#_ENREF_17)  People with disability with difficulties in communicating are at an increased risk of violence, abuse, neglect and exploitation, denial or diminished recognition of their legal capacity, reduced employment and education outcomes and social isolation.[29](#_ENREF_29) People who use AAC experience a high risk of abuse due to barriers associated with their ability to communicate but also because perpetrators target people they perceive to be isolated and unlikely to/unable to complain. This is compounded by negative perceptions and stereotypes held about people with disability that increase risk.[31](#_ENREF_31) Moreover, risk is increased where people who use AAC have not had the opportunity to develop skills in risk taking, decision making, knowledge about safety and their personal rights.[31](#_ENREF_31) People who use AAC are often socially isolated, have few communication partners that they trust or communicate with regularly and may not have a network of natural safeguards thus increasing risk of abuse[17](#_ENREF_17), [31](#_ENREF_31)  A small body of research on the risk of sexual abuse and the experiences of people who have difficulty communicating verbally and use AAC has found that people with physical disabilities who also have severe speech disorders are two to six times more likely to experience physical, mental and sexual abuse as a result of their inability to communicate effectively.[31](#_ENREF_31) Perpetrators are often known to the victim and hold positions of trust and authority (e.g. caregivers, family members, drivers)[31](#_ENREF_31)  Studies have found that children with speech/language impairments are at greater risk of abuse and neglect than children without disabilities.[33](#_ENREF_33) In particular, children with speech and language disorders had five times the risk for neglect and abuse, nearly three times the risk for sexual abuse and nearly seven times the risk of emotional abuse compared to children without disabilities. Furthermore, children with speech or language disabilities experienced the second highest prevalence of maltreatment[33](#_ENREF_33)  Barriers to identification and disclosure of abuse against people who use AAC include communication challenges; difficulties communicating with police and justice systems; discounting of the individual’s credibility; dependency on others for care and fear of withdrawal of support services.[31](#_ENREF_31) People with little or no functional speech are particularly disadvantaged in reporting violence, abuse and neglect to the judicial system as their inability to communicate effectively may be viewed as being unreliable witnesses.[30](#_ENREF_30), [32](#_ENREF_32) Moreover, communications systems such as word/symbol books and letter boards may not contain the vocabulary necessary to report an incident to police or answer questions in court[30](#_ENREF_30) | |
| Knowledge gaps | Work undertaken by Scope’s Communication Inclusion and Resource Centre has contributed to limited understanding of the intersection between complex communication needs and abuse. Barriers to reporting suggest that prevalence data concerning abuse, violence and neglect of people with communication support needs is under-estimated.[34](#_ENREF_34) Research into factors that lead to these barriers and effective strategies to increase disclosure is required. Gaps in knowledge of the prevalence and incidence of abuse, violence and neglect need to be addressed with research focused upon identifying a minimum data set capturing these factors  Research that seeks to accurately capture and reflect the extent of abuse (in all various forms) and increase the detail of information about incidents (including type, location, perpetrators) will allow development of a strong evidence base that is critical to understanding risk and protective factors and developing interventions that might prevent violence  Additionally, research is required regarding the education, vocabulary and strategies required to respond to the specific needs of people who use AAC in the prevention of abuse. Research should also investigate the use of AAC when dealing with the medical, police and justice systems  A range of systems and tools need to be available for communicating with people who have complex communication support needs; tools such as Talking Mats are necessary to facilitate and support communications[34](#_ENREF_34) and counselling.[35](#_ENREF_35) Furthermore, information needs to be in accessible concepts (e.g. words/language describing abuse in vocabularies and on communication devices) and available in culturally accessible formats[34](#_ENREF_34) [17](#_ENREF_17) | |

| **People with disability from indigenous communities** | |
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| What the literature says | Indigenous people experience significantly poorer health outcomes with rates of disability 2.4 times that of non-Indigenous people.[36](#_ENREF_36) In particular, older age groups experience a greater chronic disease burden in middle to later life and shorter life expectancy.[36](#_ENREF_36) Indigenous people have a higher prevalence of disability than non-Indigenous people with physical disability being the most common (82% of reported disability);[36](#_ENREF_36) other disabilities experienced are sight, hearing and speech related disability (42%), intellectual disability (29%) and psychological disability (28%).[36](#_ENREF_36) In 2008-09 there were 12,068 Indigenous users of specialist disability services in Australia aged 0–64 years[36](#_ENREF_36)  The interaction of relationships, environment and culture are core factors in the occurrence of abuse[9](#_ENREF_9), [37](#_ENREF_37) with the literature being in agreement that Indigenous people with disability experience greater risk of environmentally and culturally generated abuse, neglect and violence.[1](#_ENREF_1), [23](#_ENREF_23) Data from 2008 suggests that of Indigenous people who experienced physical violence in the previous twelve months, three out of five had a disability or long-term health condition.[23](#_ENREF_23) Risk factors for brain injury, including head injury, substance use and stroke are more common in Indigenous people than in the non-Indigenous population. Head trauma (due to assault) accounts for 30% of injuries requiring hospitalisation in Indigenous people compared to 18% in the general population. Between 2005-2008, Indigenous people were 21 times more likely to suffer a head injury due to assault than the general population[38](#_ENREF_38)  Available research on Indigenous people with disability suggests multiple disadvantage and significant unmet needs around access to health, life expectancy, education, income, safety, self-determination and participation in decision-making.[1](#_ENREF_1) Indigenous people with disability experience higher incarceration rates, barriers in accessing justice including adequate supports to assist in the process and challenges in reporting abuse.[1](#_ENREF_1) Inadequate regulatory oversight of the use of restrictive practices with Indigenous people with cognitive impairment in prisons is noted,[1](#_ENREF_1) particularly in terms of process, safeguards, review mechanisms and access to advocacy  Difficulties of access of Indigenous people with disability to culturally competent services with disability expertise is raised in the literature.[1](#_ENREF_1) There is no comparable word in many Indigenous languages for 'disability' which adds a significant barrier to identifying people with disability and addressing disadvantage as a result of a disability.[1](#_ENREF_1) The combination of disability and cultural background often compounds the experience of violence for Indigenous women; this includes fear of having their children taken away and feeling afraid of what might happen to the violent partner in police custody.[39](#_ENREF_39) Indigenous women are far more likely to experience violence, and experience more serious violence, than are non-Indigenous women in Australia.[13](#_ENREF_13) Furthermore, Indigenous women are less likely than non-Indigenous women to disclose their experiences of violence, with studies showing that around 90% of violence is not disclosed.[22](#_ENREF_22) Factors such as responsibility for maintaining families can result in Indigenous women “internalising and suppressing their pain and suffering”[40](#_ENREF_40)  A lack of early intervention and specialist supports around their disability and poor access to mental health services or supported accommodation for Indigenous people with disability has been associated with increased risk of neglect, exploitation and violence.[1](#_ENREF_1) Moreover, responses may mean people are removed from their home community, losing the support of family and culture, leading frequently to increased contact with the criminal justice and child protection systems[1](#_ENREF_1) |
| Knowledge gaps | National data regarding the prevalence of violence needs to be extended to capture and report upon age, gender, type of disability, place of residence and cultural background[1](#_ENREF_1)  Specific research is required to establish which service delivery models are most appropriately suited to the needs of Indigenous people. In particular, research could be undertaken in the following areas:[41](#_ENREF_41)   * Capacity-building of Indigenous people with disability and their families in relation to person-centred services and self-directed supports and models of remote service delivery * Development and dissemination of good practice in culturally appropriate service models and practices for Indigenous people with disability and their families * Sustained cultural competence training and other capacity building for mainstream disability support services in relation to working with Indigenous people with disability |

| **People with disability from culturally and linguistically diverse communities** | |
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| What the literature says | Australia has a highly diverse population comprising many cultures and languages with over 300 ancestries (cultural groups individuals identify with) captured in the 2011 census.[42](#_ENREF_42) The term people with disability from culturally and linguistically diverse (CALD) backgrounds refers to people born overseas in non-English speaking countries, and their immediate families, who may be Australian-born. Estimates suggest that there are around 1 million people from CALD background with disability[43](#_ENREF_43) although little detailed or reliable information is available on this group  People with disability from CALD backgrounds may experience greater risk of abuse, neglect and violence due to cultural stigmatism around disability[44](#_ENREF_44) and abuse (especially sexual abuse) and unwillingness to disclose or complain.[45](#_ENREF_45) In particular, people such as newly arrived migrants, refugees and humanitarian entrants may face multiple disadvantages including lack of accessible information, communication difficulties, cultural sensitivities and differences that create barriers to services and support.[23](#_ENREF_23), [45](#_ENREF_45) People with disability from CALD backgrounds are likely to experience discrimination from the wider community due to their ethnicity and discrimination from within their cultural group and the wider community due to their disability[43](#_ENREF_43)  Issues faced by individuals with disability from CALD background are considered to be poorly researched and documented. Current data does not reflect the cultural diversity of those with disabilities and can be misleading as to cultural identification of the individual (for example, based upon place of birth rather than cultural identification)[43](#_ENREF_43), [45](#_ENREF_45)  In 2012-13 there were over 27,000 people with disabilities from non-English speaking countries in supported accommodation (all forms) in Australia.[45](#_ENREF_45) One in six children in foster care with a disability has a CALD background.[45](#_ENREF_45) Those in institutional settings may be at higher risk of abuse due to lack of awareness of cultural preferences, differing perspectives upon rights and lack of awareness of Australian legal and cultural norms.[45](#_ENREF_45) For example, many parents from CALD backgrounds, particularly those from new and emerging communities, are not aware of the government policies and regulations in relation to children.[45](#_ENREF_45) Some parental conduct considered as norms within CALD communities may be unacceptable in the Australian context or may in fact be an offence[45](#_ENREF_45)  Increased risk of abuse may arise if service providers lack culturally appropriate models of care and individuals providing care to people with disability from a CALD background do not understand or appreciate cultural sensitivities, health conditions and needs of people with disability. Advocacy agencies and other supports are not equipped to meet the specific needs of this broadly diverse group, particularly in terms of assistance to find out information (in appropriate languages/formats) about culturally appropriate services, provide decision-making supports, liaise with service providers, complaints handling and incident advocacy[45](#_ENREF_45) |
| Knowledge gaps | National data regarding the prevalence of violence needs to be extended to capture age, gender, type of disability, place of residence and cultural background. This data needs to be based upon a consistent definition of disability and a combined country of birth and ancestry approach is the most useful as it captures people born in Australia but raised in a CALD family context  Additionally, research should focus upon identifying service delivery data across a range of disability cohorts and service locations to understand utilisation, equity and access of people with disability from CALD backgrounds  Research is required into developing a framework to improve culturally responsive practices in disability services |

| **People who are Deaf or hard of hearing** | |
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| What the literature says | The incidence, prevalence and nature of abuse, violence and neglect amongst people who are Deaf, have acquired deafness or are hard of hearing is largely unknown. Most available literature does not extend inquiry to this group, much less to specific sub-groups within the cohort each having different backgrounds and circumstances and therefore support needs - many Deaf people for example view themselves as belonging to a cultural and linguistic minority.[61](#_ENREF_61) Deaf children are at greater risk of neglect and abuse due to disadvantage in access to information on safety and abuse caused by the often misunderstood linguistic and cultural needs of the Deaf community[64](#_ENREF_64)  One in six Australians has some form of hearing loss from mild to profound. The percentage increases with age, most significant beyond 80 years. In Victoria, an estimated 900,000 people have a hearing loss and, in 2011, there were 2,783 sign language users[61](#_ENREF_61)  One study (2000) found 20% of deaf children were abused compared to a prevalence rate of 9% amongst the general population. Another study (2004) reported nearly 6% of deaf girls and 42% of deaf boys had been exposed to unwanted sexual experiences during childhood. Nearly half the victims reported that the abuser was deaf and half of the abusive events took place in special schools for deaf children. 49% didn’t tell anyone about the abuse, 11% told someone but were not believed[62](#_ENREF_62)  A 2011 US study found that the incidence of maltreatment, including neglect and physical and sexual abuse, is more than 25% higher among deaf and hard-of-hearing children than among hearing youths.[63](#_ENREF_63) A greater number of children who are deaf are placed in potentially abusive situations when compared to their non-deaf peer group. A high proportion of deaf children have also acquired negative self-concepts[64](#_ENREF_64) |
| Knowledge gaps | Further research is needed in:   * Sexual abuse of Deaf people in specialised education settings and within the community * How the health and legal/justice systems and mental health and aged care assessments can be tailored to ensure the full inclusion of Deaf people (including the training of skilled workers) * How communications technology can be upgraded (the cost and benefits of having all communications captioned or interpreted) to ensure the more effective inclusion of people who are Deaf, have acquired deafness or are hard of hearing[53](#_ENREF_53) * The range of information describing abuse, violence and neglect, what to do if it is experienced, and relevant safeguards, that needs to be produced in formats accessible to the different sections of this broad group |

| **People with acquired brain injury (ABI)** | |
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| What the literature says | An acquired brain injury (ABI) is damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. Impairments attributable to ABI may be temporary or permanent and cause partial or functional disability, and involve physical, cognitive or emotional changes, or psychosocial maladjustment  People with ABI can experience a restricted range of housing and support options to meet their lifetime requirements, with little choice or control over their living arrangements. Many experience prolonged inpatient hospital stays or are placed in rehabilitation facilities for extended periods[66](#_ENREF_66)  There is poor understanding of ABI in the medical, allied health and disability professions (and in the community generally). People with ABI are sometimes excluded from mainstream services because they are thought to be under the influence of alcohol or other drugs and/or mentally ill. There is very limited availability of specialist services for people with ABI in rural/remote areas.[65](#_ENREF_65)Barriers to accessing services for Aboriginal and Torres Strait Islander Australians with an ABI include different notions of health and disability, the lack of culturally acceptable and validated assessment instruments, discrimination and stigmatisation, and the lack of services in rural and remote locations[58](#_ENREF_58)  A significant factor in low levels of understanding of ABI is limited research, and in particular no research was identified on the intersection of ABI specifically with abuse, violence and neglect |
| Knowledge gaps | No research was identified that seeks to accurately capture and reflect the extent of abuse (in all various forms) and increase the detail of information about incidents (including type, location, perpetrators) amongst people with ABI  There is also need to invest in research into evidence-based outcomes of interventions and practice guidelines to prevent and respond to incidents of abuse, violence and neglect amongst this group  There is currently a lack of clarity regarding the complex interface between disability, health, aged care and allied health services for people with ABI (particularly if they have complex healthcare needs),[66](#_ENREF_66) including levels of awareness and understanding of the ABI condition amongst people working in these services (that is required in order to reduce the risk of abuse, violence or neglect for people with ABI) |

| **People with disability with no informal support networks** | |
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| What the literature says | When people with disability do not have positive family support or other natural supports there is the risk that they become wholly reliant on service providers to look out for their day-to-day wellbeing and rights (the Victorian Disability Services Act for example requires that service providers should not exercise control over all or most aspects of the life of a person with a disability).[68](#_ENREF_68) Many people with (an intellectual) disability need support, or rely upon others such as family members, to speak up about any concerns about services and supports they are receiving[68](#_ENREF_68)  Social connectivity and community inclusion have been shown to be the most effective systemic, natural safeguards for people with disabilities[52](#_ENREF_52) [68](#_ENREF_68) and when these conditions are absent the risk of abuse, violence and exploitation increases  Actions taken by families to build a safety for a member with disability include providing a loving foundation, building networks and managing relationships with support staff.[80](#_ENREF_80) The inability of formal services to substitute for some of the key roles fulfilled by families emphasises the vulnerability of those people with disability who lack strong family or other informal networks of support  However, families are not always positive supports and care is required in managing safety with families that provide negative supports as these situations may present a form of risk.[53](#_ENREF_53) This reinforces the importance of considering how to fulfil unique family functions for those without family or supports for whatever reason. Whilst services cannot replicate aspects of informal support such as long term commitment and affective support, they can support and foster development of informal relationships with people who can do this[67](#_ENREF_67) |
| Knowledge gaps | Literature reviewed within this project did not include any research that sought to accurately capture and reflect the extent of abuse (in all various forms) or increase the detail of information about incidents (including type, location, perpetrators) amongst people with disability who have no family or informal support networks or where families do not provide positive support  Further research is needed on effective ways to build and sustain social connectivity and community inclusion for people with disability |

| **People with disability at risk of familial abuse** | |
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| What the literature says | The vast majority of dangerous, abusive and violent behaviour that occurs in the privacy of people's homes is committed by men against women. The Australian Bureau of Statistics’ Personal Safety Survey (2005) found more than a million women had experienced physical or sexual assault by a male partner (current or ex) since the age of 15 and that just under half a million Australian women reported that they had experienced physical or sexual violence or sexual assault in the past 12 months8, 12  People with a disability can experience family violence, domestic violence, gender specific violence and abuse, elder abuse, hate crimes and child abuse, as well as kinds of violence and abuse that are specific to living with a disability[69](#_ENREF_69)  Family members - who may also perform carer responsibilities - are commonly identified as a key perpetrator group and can include the intimate partner or ex-partner of a woman with a disability or alternatively a father or step-father. Paid in-home carers are also a potential offender group, although not widely acknowledged in the research literature. The interface of sexual violence and domestic or family violence remains largely under-acknowledged in the research literature[43](#_ENREF_43)  Factors proposed to indicate that abuse and violence may be more likely to occur in a familial situation include caregiver stress, social isolation, power and control issues, negative attitudes towards people with a disability demonstrated by family members and high levels of personal dependency. [96](#_ENREF_43) Home-based support workers may not be inclined to report parental abuse for fear of losing their job.[53](#_ENREF_53) Home-based support workers may also face dilemma between choices people make regarding risk-taking and personal viewpoints of accountability, duty of care and safety[53](#_ENREF_53)  Financial risks associated with family members having disproportionate control over individualised funding are an emerging theme in the literature. This is covered in more detail on page 30 under *Emerging risks in packaged funding environments*. |
| Knowledge gaps | Since the literature reviewed within this project was disability focused it did not sufficiently cover any research that sought to accurately capture and reflect the incidence and prevalence of abuse (in all various forms) or increase the detail about what is known regarding risk factors in familial abuse. It is clear that there has been much work undertaken with the domestic and family violence sectors, and through current national initiatives into intimate partner violence, that will impact on people with disability. It is recommended that future work be informed by these initiatives and seek to include views and experiences of people with disability.  There is also need to research interventions and practice guidelines shown to be effective in preventing and responding to incidents of familial abuse (which may include dangerous, abusive and violent behaviour, as well as all forms of exploitation)  Failure of disability support agencies to collect data on violence, and the failure of police, family violence and justice services to collect data on disability, has further limited the potential for understanding the issues around violence against people with disabilities[70](#_ENREF_70) in familial situations |

| **Older people with disability** | |
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| What the literature says | Older people who need more paramedical help, have more complex needs, have less stable provider relationships and less backup from family and friends have been found to be at greater risk of abuse and neglect.[73](#_ENREF_73) However, as a group, older people with disability have largely been ignored within the literature (save for the need for more age-appropriate programs) and the intersection between age, disability and abuse is largely unexplored  Within the broader population, 75% of reported elder abuse cases involve the abuse of an older person with cognitive impairment.[4](#_ENREF_4), [21](#_ENREF_21) There is also some evidence that older people with dementia are abused more often by people they know, experience multiple types of assault, present behaviour signs of distress rather than verbal cues, and are easily confused and verbally manipulated by offenders[71](#_ENREF_71)  The sexual assault of older women occurs in a wide range of contexts, settings and relationships. Older women remain at higher risk of sexual assaults by husbands/partners and other family members. They can also face threats from service providers that they rely upon for general care, health care and intimate care. Assaults in such settings can be perpetrated by female as well as male staff[71](#_ENREF_71) (the study did not distinguish between the genders in the types of assault perpetrated). In 2012 the Department of Health and Ageing received notification of 378 alleged unlawful sexual contacts occurring in residential aged care facilities across Australia, almost all against women[71](#_ENREF_71)  Marsland (2015)[18](#_ENREF_18) identifies early indicators of abusive cultures in residential care services for older people with disability: these are manager behaviour, staff behaviour, individual behaviour, isolation, the service, and the care environment  Elder financial abuse is an emerging public policy challenge in Australia. Dementia and social isolation are special risk factors for elder financial abuse. Women are more likely than men to experience financial abuse – men more likely to perpetrate. The prevalence of elder financial abuse is estimated at 5-10% but under-reported due to social stigma and embarrassment.[72](#_ENREF_72) “Inheritance impatience” is a key driver of elder financial abuse, in around 66% of all cases it is the victim’s children who are the perpetrators with other family member perpetrators in around 16% of cases. Financial abuse is often tied to other forms of abuse, including emotional and/or physical. There is often a form of dependency whereby the victim trusts and/or is somehow reliant on their abuser (e.g. in the carer context) [72](#_ENREF_72) |
| Knowledge gaps | The intersection between age, disability and abuse is largely unexplored with incidence and prevalence wholly unknown  The idea of older women as victims of sexual assault is relatively recent and little understood.[71](#_ENREF_71) Significant gaps in knowledge about the sexual assault of older women are a major obstacle to the development of frameworks and strategies for prevention and intervention. There is little research on the prevalence of sexual assault of older women or the characteristics of such assaults[71](#_ENREF_71)  There is a lack of national, comprehensive data around elder financial abuse[72](#_ENREF_72) |

| **Women with disability** | |
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| What the literature says | Abuse, neglect and violence against women is currently receiving national focus, with significant work being undertaken through the *National Plan to reduce Violence against Women and their Children* including the #*OurWatch* campaign. The Victorian Royal Commission into Family Violence has also highlighted gender-related violence. Organisations such as Women with Disabilities Australia and Women with Disabilities Victoria have been instrumental in highlighting the intersection between violence towards women and disability-based violence and abuse through multiple partnerships and research projects, leading to improved understanding and clear directions for action  Women face increased risk.[43](#_ENREF_43), [56](#_ENREF_56), [74](#_ENREF_74) Various studies suggest that between 70-90% of women with disability have faced sexual abuse over the course of their lifetime and that around 40% of women are likely to be victims of family violence.[3](#_ENREF_3), [21](#_ENREF_21), [43](#_ENREF_43), [75](#_ENREF_75) Women with cognitive impairments are three times more at risk of assault and up to 10 times more likely to be sexually assaulted than women without a disability, with particular risks and vulnerabilities identified in residential settings[39](#_ENREF_39)  Women of all ages and all disability types are particularly at risk of abuse, violence and neglect.[19-21](#_ENREF_19), [40](#_ENREF_40) Women and girls with disability face structural inequality and multiple and intersecting forms of discrimination, fewer opportunities, lower status and less power than men and boys with disability.[19](#_ENREF_19), [20](#_ENREF_20), [56](#_ENREF_56), [76](#_ENREF_76), [77](#_ENREF_77) Further compounding factors include sexual orientation, homelessness, Indigenous status, cultural background and English language proficiency[56](#_ENREF_56)  Risk factors giving rise to gendered violence[43](#_ENREF_43) arise from strong association between sexist peer norms and beliefs about the status of women.[75](#_ENREF_75) The unequal distribution of power and resources and social/cultural/institutional endorsement of gender inequality are significant determinants of violence against women.[20](#_ENREF_20) A lifetime of cumulative discrimination and demeaning experiences can result in some women seeing their experiences of violence as normal and an everyday occurrence, with perpetrators reinforcing women’s expectations of violence by telling them they deserved the violence they experience[40](#_ENREF_40)  The ways in which women with disabilities experience violence includes perpetrators controlling access to medication, mobility and communication supports, threats to withdraw care or institutionalise and abuse of enduring Power of Attorney, controlling menstruation and pregnancy termination.[40](#_ENREF_40) Particular risk has also been identified where women with disability are alone with or receiving intimate care from a male support worker.[29](#_ENREF_29) Male intimate partners are the most common perpetrators of violence against women with disabilities,[55](#_ENREF_55) however male personal carers, other support staff, service providers, medical and transport staff (such as taxi drivers) and co-residents also feature highly. Perpetrators seek out partners viewed as submissive, easily controlled, or ‘deserving’ of abuse because of their disability[40](#_ENREF_40)  Women experience violence in their homes, but also in residential care settings such as emergency housing, group homes and supported residential services. Women with intellectual disability, mental ill health, severely limiting impairments, communication impairments, and living in institutional settings are at greater risk of sexual assault.[56](#_ENREF_56) Women and girls with disabilities living in institutional settings are more socially isolated and experience greater challenges in communicating and protecting themselves owing to their impairments.56 The opportunities for abusers to take advantage of those to whom they provide assistance for daily care (such as showering, toileting, dressing etc.) and transportation are considerably raised in these settings9  Under-reporting (of violence) is more likely to occur when women with disabilities live in closed or isolated settings or lack a stable home, or have poor telecommunications access or face communication barriers owing to disability, race or ethnicity.[70](#_ENREF_70) Barriers to disclosure are compounded by the nature of the impairment, attitudes to that impairment or disability, and attitudes to other aspects of a woman’s identity (her cultural background for example). Prejudicial assessments are commonly made about the competency, reliability and credibility of women with disabilities, which consequently diminishes the weight of their evidence[40](#_ENREF_40)  Many women are also unaware of the services that are available to them, including family violence and sexual assault services.[40](#_ENREF_40) Barriers to women with disability accessing domestic violence services include communication, information, attitudes, physical environment, service access and worker skills.[23](#_ENREF_23) The family violence and disability support sectors are known to be based on different theoretical frameworks and this underpins the different understandings of the experience of violence[44](#_ENREF_44) |
| Knowledge gaps | There is no systematic collection of data in Australia or within the states and territories that enables determination of the prevalence of violence against women with disabilities[78](#_ENREF_78)  There is a need for the disability sector to better understand the gendered dynamic of violence and for the family violence/sexual assault sector (including criminal justice services) to better understand and take account of the particular needs of women with disabilities[40](#_ENREF_40) [30](#_ENREF_30), [56](#_ENREF_56), [75](#_ENREF_75)  Data that is available from mainly international studies generally looks only at the extent of violence against non-institutionalised women with disabilities.[56](#_ENREF_56) Given increased risk factors known to exist in congregate and larger residential services, further research is required to identify the true extent of violence against women in disability support settings  Research is limited regarding evidence-based outcomes of interventions or practice guidelines to prevent and respond to incidents of abuse, violence and neglect against persons with disability, including particularly women with disability. There is no evidence on how to successfully roll-out programs and on how to evaluate their costs or benefits[26](#_ENREF_26), [33](#_ENREF_33)  Increased resourcing is required for cross-sector program partnerships and the development and reinforcement of links including referral pathways with mainstream and specialist services (disability, mental health, family violence, sexual assault, justice etc) |

| **Children and young people with disability** | |  |
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| What the literature says | The Royal Commission into Institutional Responses to Child Sexual Abuse is a comprehensive investigation into the abuse of and violence against children and young people. While not due to report for some months, the Royal Commission is expected to make wide ranging recommendations related to preventative systems and response to reports and incidents of child sexual assault, including how victims can best be supported. These recommendations will drive substantial changes to structures and practices, of equal relevance to children and young people with disability as all others  Abuse and neglect of children and young people with disability can range from chronic low level harassment and lack of appropriate care to extreme situations of criminal assault.[7](#_ENREF_7) Children and young people with disability experience abuse and neglect at rates higher than children who do not have disability[27](#_ENREF_27) [41](#_ENREF_41) with one study suggesting that children with disabilities are 3-4 times more likely to be maltreated than children without disabilities (with neglect being the most prevalent form of maltreatment[52](#_ENREF_52)). Another study found that children are three times more likely to experience sexual abuse than their non-disabled peers.[39](#_ENREF_39) A meta-analysis of studies of children with disability[2](#_ENREF_2) estimated that 21% of children with intellectual disability or a mental health condition experienced recent violence[2](#_ENREF_2), [26](#_ENREF_26)  Abuse occurs on multiple occasions for children with intellectual disability, communication impairments, behaviour difficulties, and sensory disability.[27](#_ENREF_27), [29](#_ENREF_29), [35](#_ENREF_35) Children with speech/language impairments are more at risk of abuse and neglect than children without disabilities[41](#_ENREF_41) and use of alternative forms of communication is also a potential risk factor as the child is less able to name/identify abuse/abusers.[34](#_ENREF_34), [35](#_ENREF_35) The rate of emotional abuse in children with disabilities is at least similar to that of physical violence[2](#_ENREF_2)  Risk factors identified by families and professionals related to the child’s impairment, lack of knowledge, risky social practices and relations; and systemic factors such as high numbers of staff unknown to a child, lack of focus on support needs and overly bureaucratic risk orientation.[80](#_ENREF_80) Another study found that children with disability being viewed negatively or expected to be compliant and/or well-behaved increased risk of abuse[34](#_ENREF_34), [35](#_ENREF_35)  Protective cultures that do not educate young people about sexuality and personal safety leave them without a language to describe abuse, which reduces likelihood of reporting and/or likelihood of an individual being considered a credible witness[35](#_ENREF_35), [79](#_ENREF_79)  Some recent Australian research has focused upon children’s perceptions of safety. Factors identified as influencing perceptions of safety include a secure foundational space (home, for most), having friends, feeling known and valued, having someone to confide in, avoiding contact with people they didn’t know and feeling able to tell someone if they felt unsafe.[80](#_ENREF_80) Concerns covered how service system operations can promote these perceptions, and how sometimes they can make it difficult for children and young people with high support needs to identify trustworthy and untrustworthy people in their lives. Professionals identified the importance of developing safety skills in children and young people[80](#_ENREF_80) | |
| Knowledge gaps | There is no systematic collection of data in Australia or within the states and territories that enables determination of the prevalence or types of violence perpetrated against children and young people with disabilities  Research with children and young people with disability that canvasses their experiences, views and ideas about safety, abuse, and about preventing abuse, is very limited and has been identified as a significant gap in knowledge[35](#_ENREF_35) | |

### Service Settings

The *Zero Tolerance Initiative* also identifies that various ‘service settings’ – the places where people receive their disability supports – may pose particular risks for people with disability. These included:

* Institutions and congregate accommodation settings
* Group homes
* Supported employment and day services
* Centre-based and in-home respite services
* Community-based one-to-one support settings.

The literature notes general agreement that people are more likely to experience abuse in a setting where they are receiving a service. This may be a formal service setting, such as a house or a centre auspiced by a provider organisation, or a community place or private residence. Experience of abuse in service settings is also more likely to involve multiple and sustained incidents of abuse, violence or neglect; perpetrators are more likely to be other service users, staff or family members.

However, again, there are significant limitations to the information and data that is available in relation to the increased risks of particular service settings, and this continues to act as a barrier to a comprehensive understanding of abuse and the development of safer environments. While some common patterns have been found in relation to abuse of people within residential care for example, much of the literature is highly generalized with little focus on settings beyond residential care. Some notable findings include:

* People living in institutional or congregate housing models may experience a lack of privacy or gender appropriate care opportunities compared with those living in other housing models, or overcrowding, invasive behaviours or a culture of abuse amongst residents [4](#_ENREF_4), [35](#_ENREF_35), [36](#_ENREF_36), [56](#_ENREF_56)
* Systemic limitations and failures, segregation and lack of choice increase risk to people with disability as institutional practices act to isolate them from local communities and long-term support relationships[80](#_ENREF_80)
* ‘Grooming’ (a predatory conduct designed to facilitate later sexual activity with a person at some disadvantage to the instigator) is likely to be more prevalent in ‘closed’ services or in locations chosen by the predator to be attractive to their target[47](#_ENREF_47)
* Individual’s with no external supports/advocates[67](#_ENREF_67) or who are living outside their local area[50](#_ENREF_50) are more likely to face increased risks of abuse
* Deaf adults with additional disabilities in residential services have high reliance upon specialised staff ie staff without advanced skills in communications or an understanding of Deaf culture can present barriers to service level actions should problems arise[53](#_ENREF_53)
* Workplaces which are also a person’s home create unique opportunities (as a result of, for example, limited oversight and scrutiny of service performance) for exploitation, abuse and neglect to occur in various forms[13](#_ENREF_13)
* There is potential for emerging risk under the individualised funding arrangements of the NDIS (e.g. failure to deliver goods and services purchased, financial exploitation, misappropriation).[13](#_ENREF_13) UK research raises the possibility that direct payment users may experience financial abuse at a higher rate than those using conventional services.[81](#_ENREF_81) Other risks are associated with the complexity of being an employer (for those who self-manage funds) and managing a budget.[13](#_ENREF_13)

The following tables provide further detail about increased vulnerabilities associated with specific service settings (gathered from available literature, noting severe limitations in many areas):

| **Residential settings (institutions, large congregate care settings, group homes)** | |
| --- | --- |
| What the literature says | The Disability Services Commissioner noted that of 540 complaints received in 2014-15, the largest proportion related to shared supported accommodation (42%).[39](#_ENREF_39) From 2010 to 2014, the Public Advocate (Victoria) received 87 notifications regarding violence or abuse in residential services, the majority involving resident to resident and staff to resident violence. According to the Public Advocate, contributing factors included resident incompatibility/lack of residential options, staff difficulties in managing challenging behaviours, inadequate resources/staff training, casualisation of the workforce, and challenging rosters/demanding workloads [86](#_ENREF_86)  Numerous studies report that violence may be more common for people with disability living in institutions or large residential services.[21](#_ENREF_21), [38](#_ENREF_38) Institutional and residential settings combine a number of risk factors that increase susceptibility to abuse, violence and neglect[21](#_ENREF_21), [38](#_ENREF_38), [82](#_ENREF_82) including higher likelihood of numerous perpetrators and more frequent/multiple episodes of abuse.[21](#_ENREF_21) Facility location issues including isolation from broader community, and location of people away from their local area are also contributing factors[50](#_ENREF_50)  Studies report high levels of sexual abuse in residential homes with other residents and staff being identified as the primary perpetrators.[29](#_ENREF_29), [39](#_ENREF_39) Power imbalance between residents and staff in institutional/congregate housing models is a significant factor: institutional and residential services provide opportunities for staff to abuse their power over residents.[56](#_ENREF_56) Grooming is of marked concern in institutional environments[48](#_ENREF_48)  Other features of residential settings found to increase risk of abuse and violence include individuals having little or no control over daily routines and activities; relying on others for personal care (particularly where they have little choice of provider or where multiple providers are involved); and lack of privacy/gender appropriate care opportunities. [5](#_ENREF_5), [21](#_ENREF_21), [27](#_ENREF_27), [35](#_ENREF_35) Residential settings where there is overcrowding or invasive behaviours amongst residents can also contribute to a culture of abuse between residents [4](#_ENREF_4), [35](#_ENREF_35), [36](#_ENREF_36), [56](#_ENREF_56)  Poor management may inadvertently foster the development of abuse - institutional violence often involves rigid regimes, poor quality care, unethical or unauthorised practices in response to challenging behaviours and breaches of professional boundaries by staff.[56](#_ENREF_56) Service operations that demand efficiencies resulting in resident incompatibility, inappropriate housing placements and/or restricted choices in housing or co-residents may also contribute to abuse and violence[83](#_ENREF_83), [84](#_ENREF_84)  Workforce factors are implicated in risk of abuse of people with disability across a range of accommodation models. These include lack of skill in supporting active engagement of residents;[56](#_ENREF_56), [85](#_ENREF_85) low pay rates, high staff turnover, high use of casual staff, lack of pre-recruitment screening, and ineffective supervision and training.[3](#_ENREF_3), [27](#_ENREF_27), [30](#_ENREF_30) System deficiencies that fail to prevent perpetrators moving between locations or obtaining employment elsewhere in the system have also been found to increase risk [3](#_ENREF_3), [21](#_ENREF_21)  Women with disabilities in institutional and residential settings may experience abuse, violence, sexual assault.[56](#_ENREF_56), [39](#_ENREF_39) In these settings, women are more socially isolated and experience greater challenges in communicating and protecting themselves.[56](#_ENREF_56) The opportunities for abusers to take advantage of those to whom they provide assistance for daily care (such as showering, toileting, dressing etc.) and transportation are considerably raised [9](#_ENREF_9), [70](#_ENREF_70) |
| Knowledge gaps | Abuse is likely to be under-reported[4](#_ENREF_4), [21](#_ENREF_21) particularly in many institutional/residential settings[29](#_ENREF_29) therefore precluding a true picture of the incidence and prevalence of abuse and violence in residential settings. Little is known about the factors that lead to under-reporting or non-disclosure of incidents and effective strategies to increase reporting  There is no systematic collection of data in Australia or within the states and territories that enables determination of the prevalence or types of violence perpetrated against people with disability across different types of residential setting  Grooming incidence and prevalence data is extremely limited and its occurrence under-reported[49](#_ENREF_49)  More and higher quality research is required particularly in relation to the range of service settings for forms of disability other than intellectual disability, such as physical or sensory impairment and mental health conditions[26](#_ENREF_26)  For women with disability, the available data only looks at the extent of violence against non-institutionalised individuals (where analyses and studies consistently find that women with disabilities are at greater risk of violence than men with disabilities and experience violence at up to double the rate of women without disabilities). There is no consistent and inclusive national data available on the intersection of gender, disability and violence across all spatial domains (institutional and community living) to enable reliable ongoing trend analysis into the prevalence and incidence of violence in disability services[56](#_ENREF_56)  Research is limited regarding evidence-based outcomes of interventions or practice guidelines to prevent and respond to incidents of abuse, violence and neglect across different service settings. There is no evidence on how to successfully roll-out programs or on how to evaluate their costs or benefits[26](#_ENREF_26), [33](#_ENREF_33) in institutional or residential service settings. |

| **Other formal service settings (supported employment, day services, centre-based respite)** | |
| --- | --- |
| What the literature says | Of 540 complaints received by the Disability Services Commissioner in 2014-15, 18% related to people’s individual support packages, 12% to day services, 9% to case management and 8% to respite services [39](#_ENREF_39) [92](#_ENREF_92) (the balance, the largest proportion, related to shared supported accommodation)  The literature provides very little information specific to particular settings (such as supported employment, day programs and centre-based respite services) other than residential care. Most setting-related risk factors noted in the literature were highly generalised and could be applied to all settings where disability support services may be provided, including supported employment, day services and centre-based respite. Such factors included:   * Individuals with no external supports or advocates[67](#_ENREF_67) or who are living outside their local area[50](#_ENREF_50) are more likely to experience abuse or harm * Poor care cultures within services of all types can encourage well-intentioned staff practices to deteriorate or may allow intentional abuse to remain unreported/hidden[38](#_ENREF_38) (attitudes that de-value people with disability shape individual carer behaviours and contribute to institutional barriers to eliminating abuse and violence)[3](#_ENREF_3) * Similarly, environments that readily accept excuses for abuse, have low accountability, little outside scrutiny, a closed culture or that cover-up of reports of abuse or fail to protect those who report[27](#_ENREF_27), [35](#_ENREF_35), [36](#_ENREF_36), [38](#_ENREF_38) or that neutralise normal moral concerns[36](#_ENREF_36) will allow abuse to flourish. Cultures that characterise criminal actions (e.g. rape, assault, false imprisonment, theft) as abuse or that locate the event in a service context rather than a criminal context (for example, treating criminal actions as policy issues, a staff training or behaviour management issue)[35](#_ENREF_35), [36](#_ENREF_36) fail in achieving optimal levels of prevention * Services of any type, delivered in any place, that employ therapeutic practices that would be seen in any other area of service as unlawful (e.g. certain restrictive practices) take away or restrict personal rights[3](#_ENREF_3), [5](#_ENREF_5), [21](#_ENREF_21), [27](#_ENREF_27) * Information promoting understanding of abuse and steps that can be taken to respond needs to be available in Easy English and be culturally accessible[93](#_ENREF_93) across service settings if it is to be effective in assisting to prevent abuse and neglect |
| Knowledge gaps | There is little direct information available in the literature on risk factors or incidence and prevalence of abuse specific to supported employment, day programs or centre-based respite service settings |

| **Emerging risks in packaged funding environments** | |
| --- | --- |
| What the literature says | The increasing use of individualised funding packages and in particular the service reform embodied within the National Disability Insurance Scheme (NDIS) is increasing choice, control and flexibility of how and when people access disability supports. However, increased use of home and community based services delivered with limited or no worker/carer supervision or oversight presents new forms of risk that require understanding and mitigation strategies. The increase in self management of funds or management by family members also requires appropriate safeguards to insure that risk of exploitation and financial abuse is addressed.  Personal budget programs and self-directed care incorporate higher potential for risk around poorer quality services (e.g. untrained, unregulated personal attendants); budget management and employment responsibilities; misuse of funds/financial abuse from family or paid carers; and breakdown of care arrangements and contingency planning[17](#_ENREF_17)  An overview of individual budget schemes in the UK also found that service users may potentially be at risk to family and care workers operating in the uncertain area of providing paid support in the context of other relationships.[90](#_ENREF_90) Similarly, another study found risks relating to employing close friends in particular the difficulty the person with disability would face in disciplining or terminating their employment[81](#_ENREF_81)  Direct payment and self-directed care programs potentially increase a person’s vulnerability to abuse/exploitation as recipients draw from an unregulated market and with little experience as an employer, may employ support workers who work alone in their home and who may not have undergone a criminal record check.[81](#_ENREF_81) High turnover in support workers, lack of training and increased trends towards casual staffing all also increase risk;[80](#_ENREF_80) a highly casualised workforce may side-step the usual probity checks regime and/or supervision and training and occur outside of supervisory/support layers[53](#_ENREF_53)  Risks to people who self-direct include ‘befriending’ by those who target people who appear to have less power, leading to exploitation and risk of fraud/scams.[81](#_ENREF_81) One study found that arrangements posing least risk of financial exploitation were those involving steady partnerships (e.g. parents of young or adult children with disability) or professional guardians (e.g. solicitors or accountants)[81](#_ENREF_81)  The personal care market is immature, lacking in choice (making hire and fire difficult in practice) and presents supply issues for rural/remote residents. Research in the UK found that the emergence of an unregulated ‘grey’ market is a risk with poor employment conditions, training and low wages[90](#_ENREF_90) making quality assurance all the more difficult  Where a market becomes fragmented and services (and users) are devolved, a collective voice to shape, develop and regulate services might be lost.[91](#_ENREF_91) Where an individual is dependent on a particular support worker, or even a single broker/provider, he/she has little recourse to address concerns or issues that may arise.[36](#_ENREF_36) Support services delivered by independent user-led peer support and advocacy organisations and community-based voluntary sector agencies have been shown to play an important part in enabling people to take risks to increase their independence as well as acting as sources of support and advice on keeping safe[90](#_ENREF_90) |
| Knowledge gaps | Despite deep concern amongst consumer groups and representative bodies regarding safeguarding under a fully operational NDIS, service user views are largely absent in the literature  The evidence base on the possible consequences of expanding the market of personal carers is not yet robust enough to offer conclusive ﬁndings  The link between risk and consumer-directed care is poorly explored and more research is needed to develop sound risk management strategies.[73](#_ENREF_73) UK authorities conclude that while safeguarding is frequently raised as an issue, there is no evidence as yet that people taking up self-directed support, including direct payments, are at greater or lesser risk of harm. The move to self-directed support however should be accompanied by better ways to identify and manage risks[90](#_ENREF_90) including more research on risk-enablement practices[90](#_ENREF_90)  Promotion of choice and control, particularly through the use of personal budgets and self-directed care, requires a change in the way risk is understood, managed and negotiated with the person using the service. It also implies the need for organisational transformation to respond to person-centred ways of working in all aspects of adult social care, including safeguarding[90](#_ENREF_90)  Service users need to be able to define their own risks and be empowered to recognise and identify abuse, neglect and safeguarding issues with the support of frontline staff. People need clear information and advice about what to do if they have concerns[17](#_ENREF_17) |

| **Personal and intimate care** | |
| --- | --- |
| What the literature says | Intimate and personal care is a major area of support and service provision for people with disability, particularly those with profound and multiple disability.[87](#_ENREF_87) The provision of intimate and personal care raises issues for both the individual with disability and their staff and carers, including around personal space, privacy, sexuality and sexual expression[88](#_ENREF_88)  Particular risk has been identified where women with disability are alone with or receiving intimate care from a male support worker.[29](#_ENREF_29) Gender is important but culture and sexuality need also to be considered when matching carers and individuals.[88](#_ENREF_88) Amongst people with learning disabilities, same-gender personal care has been found to largely protect women from the risk of sexual abuse but fail to protect men.[88](#_ENREF_88) Same-gender personal care however may raise issues about potential risk from staff who identify as gay or lesbian[88](#_ENREF_88) when providing same-sex intimate care  Services designed around inclusive support practices may not recognise that some individuals have specific and highly personalised support preferences; and may embody approaches to personal or intimate care that may not be culturally or ethnically appropriate.[87](#_ENREF_87) Further, personal and intimate care tends not to be specifically detailed in job requirements or duty lists and thus may rely upon individual staff members’ perceptions or own experiences as to what constitutes good practice[87](#_ENREF_87)  Service response issues have been recognised in relation to how women with intellectual disability tend to see their bodies in negative ways and the role of women staff in relation to men with intellectual disability who have difficult sexual behaviour.[87](#_ENREF_87) Intimate/personal care is considered best carried out by workers of the same-gender as the individual. However, as women predominate in carer roles, cross-gender care may be the only option at times due to rostering, staff availability etc[88](#_ENREF_88) |
| Knowledge gaps | Management and practice of personal and intimate care has largely been neglected in the literature outside the use of individual guidelines and same-gender intimate care policies, with little research evidence or theoretical literature to inform the planning, conduct and organization of associated care tasks[87](#_ENREF_87)  Further research is required to identify what constitutes good practice when supporting individuals in many areas of daily living,[87](#_ENREF_87) including what constitutes effective, individualized and appropriate practices[87](#_ENREF_87) in personal and intimate care. Policies need to not only address the mechanics of providing intimate and personal care but also to look at holistic needs covering such things as self-image, identity and sexuality[88](#_ENREF_88) to ensure that it is provided according to individual preference. |

## What can be done?

### The Bigger Picture

The literature raises a number of ‘big picture’ issues that place some context around abuse, violence and neglect and further our understanding of the forces that shape our culture. These have significant implications for any future national approach to ensuring people with disability can live full active lives in the community whilst minimising risk of abuse and violence. Specifically:

* The way in which disability is understood has significant implications for recognising, and responding to violence against people with disability[21](#_ENREF_21), [27](#_ENREF_27), [36](#_ENREF_36)
* Broad social acceptance of a group having less access to their rights and having difficulty in having those rights upheld, allows systems to develop which, mostly unintentionally, allow abuse to thrive[36](#_ENREF_36)
* ‘Ableism’, the tendency for some to see able-bodied people as the norm, results in “systemic, structural, intersecting and individual forms of discrimination against and exclusion of people with disability.” [21](#_ENREF_21) Because they don’t fit this ideal, people with disability are “often treated as less than fully human”[21](#_ENREF_21) and deprived of the rights and protections afforded to other members of society
* Some suggest that legislation, policy and service frameworks fail to clearly understand, describe or recognise violence against people with disability with the result that people with disability are given less protection than those without disability.[21](#_ENREF_21) Policy responses in violence, domestic violence and sexual assault have failed to achieve universal access (i.e. to be inclusive of people with disability)[75](#_ENREF_75)
* Continuing exclusion of people with disability from public health policy[75](#_ENREF_75) and generic preventative health strategies has led to an absence of these strategies in disability policy[94](#_ENREF_94)
* Lack of interagency coordination of disclosures of abuse, neglect and exploitation of people with disability, particularly with respect to children[35](#_ENREF_35), contribute to failure to build a fully functioning safeguarding system
* Significant barriers in legal, justice and policing systems preclude access by people with disability and lower the likelihood of successfully preventing and responding to incidents of abuse or violence.[36](#_ENREF_36)
* Violence against people with disability must consistently be identified as a denial of and violation of human rights and in contravention to Australia’s commitment to international human rights obligations.[21](#_ENREF_21)
* These suggest that more broadly governments should be contributing to, and working towards ‘universal prevention’ by raising public awareness about violence and people with disability and strengthening local protective networks for people with disability;[27](#_ENREF_27), [30](#_ENREF_30) and leading or supporting campaigns that promote gender equality[26](#_ENREF_26) and that seek to change cultural and social norms that support violence.[26](#_ENREF_26)

### System and Service Features

The literature reviewed for this report shows that a service system designed to reduce the risk of people with disability being subjected to abuse, harm and neglect will:

* Prioritise and target prevention[26](#_ENREF_26), [33](#_ENREF_33), [37](#_ENREF_37)and address early warning signs (such as reducing isolation, and asking people how they feel), recognising ways in which people may express their experiences[38](#_ENREF_38)
* Strengthen individual capability through empowerment, information and choice[25](#_ENREF_25) [16](#_ENREF_16), [39](#_ENREF_39)
* Appropriately respond to individual incidences of harm that occur[27](#_ENREF_27)
* Balance choice and independence with responses that seek to achieve personal safety through over-protection or having control unnecessarily placed with others[27](#_ENREF_27)
* Work across sectors to tackle the causes of abuse rather than just the symptoms.[36](#_ENREF_36)

These findings are reflected in the five-tiered *Zero Tolerance* framework and appear to affirm work undertaken to date. Within this framework, and drawing upon advice from the expert committees guiding this project, service providers should consider the following initiatives to contribute to reducing abuse, harm and neglect of people with disability:

### Person-centred approaches, empowerment and choice

* Provide opportunities for people with disabilities to discuss their views on safety, harm and risk both privately and in peer-led environments[53](#_ENREF_53)
* Provide rights based education that provides people with disability with knowledge and skills for personal empowerment, protective behaviours and understanding of experiences that may be abusive[36](#_ENREF_36), [97](#_ENREF_97)
* Ensure people with disability have access to training to assist them to recognise violence, abuse and neglect so they can self-report[3](#_ENREF_3)
* Strengthen individuals’ capabilities to exercise control and choice[16](#_ENREF_16), [25](#_ENREF_25), [36](#_ENREF_36) by developing skills and capabilities in recognising and managing risk, including risk-taking.

### Family and community connections

* Encourage the presence of engaged, supportive people in a person’s life[5](#_ENREF_5), [36](#_ENREF_36), [39](#_ENREF_39)
* Recognise and encourage the value of unpaid relationships and meaningful community engagement.[5](#_ENREF_5), [36](#_ENREF_36), [39](#_ENREF_39)

### Service culture, management and operations

* View analysis of critical incidents from a learning perspective rather than a compliance or audit perspective[36](#_ENREF_36)
* Shift culture, attitudes and relationships within services away from procedural/managerial ‘audit’ style responses to addressing abuse in services[36](#_ENREF_36), [39](#_ENREF_39) including support for ‘speaking out’
* Staff training to include mandatory rights based training to develop core competency skills in recognising and reporting violence, abuse and neglect of people with disability[3](#_ENREF_3) [39](#_ENREF_39)
* Whenever possible, involve people with disability who disclose experiencing violence in the response process, providing them with choices about what steps are taken and who is contacted.

These points (and others from the literature) have been used to develop a series of Fact Sheets for service providers that may assist them to enhance safety for service users, across different cohorts of people with disability and particular service settings – see Appendix B.

## Findings

### Policy Frameworks

1. **Finding**: A holistic, universal, prevention-focussed approach to safeguarding and abuse prevention is required to ensure people with disability have their human rights upheld. A focus on best practice in individual rights and abuse prevention will assist with transition to the new NDIS quality and safeguarding framework.

### Data collection and abuse prevalence

1. **Finding**: The limitations of available data on abuse and neglect of people with disability are well reported in the literature with consensus that what is known is likely to be under-reported. These limitations are not confined to people in disability services. This report found that ‘next level’ data was even more limited, meaning that data that provides a nuanced understanding of risk for specific cohorts of people with disability, and within specified service environments is not readily available.

Improved data collection is recognised as one of the steps necessary to understanding abuse, developing preventive policies and systems and creating safe environments. Data collection needs to include:

* 1. prevalence of abuse, neglect, violence and exploitation
  2. age, gender, type of disability, place of residence and cultural background of victims (where provided and consented to)
  3. any perpetrator characteristics including relationship with victim
  4. nature of abuse
  5. location including service setting and geographical location

### Risk focussed practice development and outcome monitoring

1. **Finding**: Research is limited regarding evidence-based outcomes of interventions to prevent and respond to incidents of abuse, violence and neglect against people with disability. Whilst specific strategies for women and children are being explored as part of national inquiries and royal commissions, it is still limited. There is little-to-no evidence on how to successfully roll-out programs or on the costs or benefits of different approaches for other identified cohorts or settings. Methodologies to prevent abuse must be evidence based and evaluated to improve understanding of impact and inform future investment, including:
   1. perspectives of people with disability on their experiences, views and ideas about feeling safe and being safe which are representative of the diverse disability community
   2. consideration of cost-benefit analysis
   3. outcome measures

### Empowerment of people with disability

1. **Finding**: When considering risk of harm broadly, the evidence is clear that strengthening individual capability through empowerment, information and choice will contribute to reducing the risk of harm for people with disability.

Capacity building should include education, training and peer support for and by people with disability which focuses on rights; how to recognise abuse, violence and neglect; what to do about it; and how to report it in accessible concepts and culturally accessible formats. There is also a need for education and resources about sexuality and respectful relationships. Parallel information for service staff and families to support this capacity building and build more capacity in the sector are also required.

### Cohorts of people with disability

1. **Finding**:The literature revealed significant gaps for understanding risk for people with disability generally, and strategies that might mitigate those risks.

There was clear evidence that people with intellectual disability face increased risk of abuse in comparison to people without disability and those with physical disability. Several Victorian initiatives are in place to develop tailored resources for people with intellectual disability about rights and self advocacy, and speaking up about abuse and neglect. These include VALID’s *Staying Safe* training program and SCOPE’s *Speak up to be safe from abuse.*

Other initiatives in Victoria focus on the intersection of violence, disability and gender and on the experience of abuse for children. These include Women with Disability Victoria’s *Workforce Development Program on Gender and Disability* and Association for Children with Disabilities’ *Keeping Children Safe*. More work is required to build the capacity of mainstream services, and build in gender and age responsive approaches into specialist services. An example is the need for increased focus on grooming of children and adults with disability. Emerging lessons from the *Royal Commission into Institutional Responses to Child Sexual Abuse* show that better understanding of personal and professional boundaries can reduce grooming opportunities.

More pertinently for this report, knowledge and strategies for other identified cohorts of people with disability are strongly under-represented, highlighting the need for:

* Focus on human rights and prevention of abuse of people who use augmentative and alternative communication (AAC), including use of AAC within disability, medical and justice systems.
* Addressing the significant gap in understanding and actions on safety and risk of harm for **people with disability from Indigenous and CALD backgrounds** through engagement and co-design with these communities and their support networks
* Research into the specific risks of harm faced by **people with an acquired brain injury** through their experiences of the interface between disability, health, aged care and allied health services.
* Multiple references to mental health in the literature highlighted that there may be unique factors that increase risk for people with dual disability.

### Disability Service Settings (existing and emerging)

1. **Finding**: The majority of evidence regarding disability service settings highlights the need for holistic, human rights-based approaches by disability service providers, with person-centred policy and practice and open and transparent cultures. This reinforces the universal approaches advocated through the *Zero Tolerance* Framework.

‘Next level’ data typically focuses on accommodation settings, with a focus on the features of institutional and group home cultures. Data and evidence around risk in centre-based service settings (including day and respite centres and disability employment services) is limited-to- non-existent. Evidence around risk of harm and safe provision of community based services – including for people receiving services in their own homes – was not found in the literature.

More work needs to be done in the lead up to the NDIS to understand the risks associated with providing support in individualised service settings, where informal support is being provided by informal networks, or where support is delivered ‘remotely’ (with limited or no direct supervision). Research within parallel human service sectors such as aged care and health may assist. This should include emerging technological and human resource responses to remote supervision, training and workplace culture development for workers in a range of settings.

Resources to provide guidance on what constitutes good practice when supporting individuals in many areas of daily living, including what constitutes effective, individualized and appropriate practices in personal and intimate care are also required.

## Appendix A:

### NDS Zero Tolerance Framework

## Endnotes

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