

# People living with Acquired Brain Injury

A submission to the Disability Royal Commission on the experience of people living with acquired brain injury and risk of violence, abuse, neglect and exploitation

**Leadership<sup>+</sup>  
Plus**

PO Box 190

Richmond, VIC 3121

[admin@leadershipplus.com](mailto:admin@leadershipplus.com)

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## About Leadership Plus

Leadership Plus is a Disability Advocacy organisation supporting people with disabilities throughout Victoria. We are a team of advocates and decision supporters who advocate for approximately 300 people each year, with a particular focus on those living with acquired brain injury.

Leadership Plus was formed after a merger between Headway Inc, an advocacy group specialising in issues and supports for people with acquired brain injury (ABI) and Action for Community Living, an advocacy group with a history of working on individual and systematic issues associated with daily living support needs.

## Acknowledgements

The Leadership Plus submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is informed by our knowledge and experience of providing independent advocacy, personal development and capacity building to people living with ABI over four decades and the collective knowledge and experience of individual advocates across a number of independent disability advocacy agencies in Australia.

The content of this submission also draws on the lived experience of people with Acquired Brain Injury (ABI). Leadership Plus organised and facilitated four workshops with people with Acquired Brain Injury (ABI) to assist the commission understand their experiences and what they thought the Disability Royal Commission on Violence, Abuse, Neglect and Exploitation of People with Disabilities (DRC) should know. The report ***Hear My Voice*** (Appendix 1), developed by Leadership Plus based on these workshops is submitted as an accompanying document to this submission called ***Hear My Voice*** and should be read alongside positions outlined in this submission.

Leadership Plus also acknowledges the support of Paul Ramcharan in collecting appropriate data and helping us to write this submission.

Leadership Plus also draws on the work done in response to the Victorian Royal Commission into Family Violence, ***Everybody Matters***<sup>i</sup>, a document that sets out clearly how to address the gap between the experience of family violence and both policy and practice. It is a document recommended to the DRC as helpful to the DRC's aim of addressing violence, abuse, neglect and exploitation of people with disability. Finally, Leadership Plus supports the submissions made to the DRC by Disability Advocacy Victoria<sup>ii</sup> and Disability Advocacy Network Australia<sup>iii</sup>.

## Key Terms and Definitions

**Ableism** - Ableism refers to a set of beliefs and practices about 'typical' or 'normal' abilities and feeds discriminatory attitudes and the refusal to adapt to the needs of people judged as inferior or 'abnormal'<sup>iv</sup>.

**Hidden disability** – brain injury is a hidden disability. The physical injuries following brain injury can be quite easy to see but disabilities that affect thinking, emotion and behaviour can be far harder to recognise. Leadership Plus also recognises that where systems do not recognise the wishes and needs of people living with ABI then these needs are effectively unseen. We make this point throughout this submission in relation to assessment, understanding key dimensions of living with

ABI and in relation to appropriate services and access to those services. For these reasons, Leadership Plus, and others, refer to brain injury as a hidden disability<sup>v</sup>.

Intersectionality - A theoretical approach that understands the interconnected nature of social categorisations – such as gender, sexual orientation, ethnicity, language, religion, class, socioeconomic status, gender identity, ability or age – which create overlapping and interdependent systems of discrimination or disadvantage for either an individual or group (Everybody Matters, <sup>vi</sup> p.4).

## Executive Summary

The experiences of people living with Acquired Brain Injury are not well understood and the implications this has on their lives are little known. In this submission Leadership Plus has identified challenges and systemic issues faced by people with ABI whose needs are poorly met by current systems and environments. The unique differences in their experience include:

- Adapting to new lives and identities subsequent to acquiring their disability.
- Changes to relationships with friends, family, work and elsewhere as a result.
- An experience of rejection by the community and experience of ableist attitudes for their 'hidden' disability.
- A loss of reliable, consistent and appropriate support and breakdown of social networks compounded by the closure of peer support groups in the community.
- A struggle to absorb and process information and to make decisions without support.
- Too few people living with ABI independently in the community access disability services through the NDIS.
- There continues to be inappropriate accommodation in the community and people with ABI face the risk of homelessness. Boarding houses and Special Residential Services (SRS) show much higher rates of violence and abuse. Without advocacy and other meaningful housing support, people continue to experience low levels of disability support and higher levels of violence and abuse.
- Discharge planning can lead to people entering residential aged care, nursing homes or crisis care units. Inappropriate housing can lead to neglect and resistance of the NDIS to take responsibility can leave people at risk over significant period during which they might continue to experience neglect and violence.
- Struggles to access education, training and employment with additional challenges with maintaining benefits payments mean many people live in poverty and precarity. They do not have the resources to support them to change their lives and pursue other choices.
- Greater likelihood of being 'embroiled' in the criminal justice system and lack of consistent support and advocacy in relation to these experiences.
- A lack of knowledge about how to complain or to access disability advocacy support.

There is an inevitability that circumstances and experiences such as these lead to a number of risks - isolation, exclusion, discrimination, homelessness, lack/loss of income and support, contact with the justice system. These in turn significantly increase the risk of violence and abuse. But there is a gap between the circumstances that create these risks and the solutions that address them. Leadership Plus recommends that each of the above experiences need policy and practice solutions as laid out in recommendations throughout this submission.

## Leadership Plus Recommendations

### Recommendation 1: Specialist Support

**When considering the needs of the “disability community” we must consider both the nature of the disability as well as the impact resulting from the intersectionality of the lived experience. The “disability community” is diverse and as such, requires a service system that understands this complexity.**

As stated in *Everybody Matters* (2018) Leadership Plus believes:

*‘Systemic **marginalisation** is the result of policies, processes, procedures and practices which operate in a manner that creates **inequality** by privileging the dominant group and reinforcing the **exclusion** of other groups. **Systemic bias** and **discrimination** result when the system creates processes that exclude some groups or individuals. Systemic bias can appear subtle or be invisible to members of the dominant group because it preferences their societal norms. **Systemic bias** and **discrimination** create barriers that prevent marginalised individuals or groups from having equal access to resources and services. Access and equity are key objectives...’, The State of Victoria (Family Safety Victoria), 2018<sup>vii</sup>, p.25).*

The needs of people living with ABI are distinct and unique and this demands a workforce that is specialised in approach. Leadership Plus argues generalised disability support service delivery does not meet these demands. Encouraging specialisation and the building of capacity to understand the experience of and significant risks faced by people living with ABI, needs to include:

a) Specialist training in relation to the unique experiences of people living with ABI and relevance to:

- The NDIS
- The broader Community Service Sector
- NDIS Service Providers
- Health, Hospital and Medical services
- The Justice System

b) Specialist ABI Case Management

The nature of and impact of disability through acquiring a brain injury generally results in the need to navigate the acute health system, hospital and medical services, rehabilitation, and community services over a period of several years and for many, lifelong. This journey is difficult, confusing, complex, disempowering and life changing.

c) Specialist ABI Case Management would work to identify and/or address:

- The need for a single point of contact
- The need for information, options, and future planning
- Understanding rights and entitlements regarding the community and disability support service structure
- Risk of violence, abuse, neglect, and exploitation
- Risk of homelessness
- Risk of isolation
- Risk of entering the Justice System

- Further, in relation to disability advocacy, ‘many cases of violence and abuse involve numerous parties and a complex series of interactions across many domains, which need to be coordinated’ (DAV, 2022, paragraph 142, p. 39<sup>viii</sup>), (please also refer to Recommendation 5: Crisis Management).

### Recommendation 2: Decision Support

**As an organisation successfully delivering the Decision Support Pilot program (2018-2022) funded by the Commonwealth Department of Social Services, Leadership Plus continues to campaign for expanded independent decision support services to be made available at a suitable scale to genuinely support the demand that has been demonstrated by the decision support pilots.**

It is recommended that Commonwealth government, along with States and Territories, ensure that Supported Decision Making:

- is made available where people living with ABI require this support
- is available for all potential and current NDIS participants, in line with obligations under the United Nations Convention on the Rights of Persons with Disabilities
- continues to be funded beyond the pilot stage by establishing an ongoing funding stream, as recommended in DANA’s submission to the DRC (DANA<sup>x</sup>, 2022, p.15, para 4d.)
- is provided by independent advocacy organisations with no conflict of interest, autonomous of the NDIS structure, and
- has an oversight mechanism embedded in the relevant State/Territory Office of Public Advocate, ensuring the quality of the service being provided.

### Recommendation 3: Human Rights

It is vital to protect, defend and ensure all human rights set out in the Convention on the Rights of Persons with Disabilities along with other human rights. Leadership Plus agrees with the statement in ***Everybody Matters*** (The State of Victoria (Family Safety Victoria) 2018) <sup>x</sup> as it relates to family violence,

*‘A human rights framework must be at the heart of everything we do, because [sic violence and abuse] are a significant violation of human rights. The way we respond to individuals and families must be strengths-based and trauma-informed to respond to the impacts of trauma and must recognise and respect the strengths of an individual. It also must be person-centred to support the person within their unique context to exercise their rights, choices, and preferences. Embedding cultural safety must be a paramount responsibility for all services’* (p.37).

Leadership Plus feels the same can be applied to people living with Acquired Brain Injury (ABI). We highlight the following priorities in relation to people living with ABI.

As a priority Leadership Plus calls on the state governments to commit to:

- funding for provision of **safe housing**, with security of tenure for people living with ABI
- end the practice of placing people with ABI in inappropriate housing such as residential aged care, nursing homes, boarding houses, and crisis accommodation for extended periods and, as suggested by DANA, ‘introduce new legislation to provide right of entry of disability advocates for closed or institutional settings’ (DANA<sup>xi</sup>, 2022, p.15)



- secure **income support** by ensuring appropriate systems and supports are in place for people with ABI to access training, education, and employment support and to apply for and access the Disability Support Pension (DSP). Further, Leadership Plus agrees with the DAV (2022) <sup>xii</sup> recommendations, in accordance with Australia’s obligations under S.42 of the United Nations *Convention on the Rights of Persons with Disabilities* that it should develop a 10-year plan to ‘end segregated education’ and ‘end segregated employment facilities, ensuring such facilities are replaced with further supported employment training programs’ (DAV<sup>xiii</sup>, 2022, p. 6).

#### Recommendation 4: Peer Support and Self-advocacy

We endorse Disability Advocacy Victoria’s recommendation made in their submission to the DRC (DAV<sup>xiv</sup>, 2022, recommendation 15, p.9 and paragraphs 188-190, pp48-49) regarding the important work done within the disability self-advocacy movement and peer support networks. The safeguarding role and associated benefits delivered by the disability self-advocacy and peer support networks cannot be underestimated, with demonstrated effectiveness in building social and support networks that provide an invaluable contribution to address the experience of isolation and exclusion.

Leadership Plus calls on State, Territory and Commonwealth governments to commit to:

- ongoing funding and provision of self-advocacy and peer support networks
- working with people living with disability, self-advocates, and peer support groups in co-designing in all policy initiatives.

**Hear My Voice**, our companion volume for this submission (Appendix 1) provides an example of how valuable this approach can be in highlighting the voices and experiences of people living with ABI and how this drives our recommendations and highlights how codesign establishes strong grounds and mechanisms for change.

#### Recommendation 5: Crisis Management

Mechanisms and processes need to be established, with rapid response times, to enable dedicated and targeted support for those who are identified as experiencing elevated risk of violence and abuse when a crisis arises and, additionally, to navigate a response for people who do not have access to NDIS.

As DANA suggests in its submission to the Disability Royal Commission it would be helpful to ‘establish a mechanism to enable organisations to provide dedicated ‘safeguarding advocacy for people with disability who are identified as experiencing elevated risk of violence, abuse, neglect and exploitation’ (DANA, 2022,p. 15<sup>xv</sup>).

Please also refer to Recommendation 1: Specialist Support; Specialist ABI Case Management.

The absence of crisis response in the current NDIS framework is of significant concern and requires action. The current process requiring a Change of Circumstance to be lodged, with a 21 day wait on the decision by the NDIA, is inadequate and may seriously compromise the safety of a person with disability, leaving them at risk of violence and abuse.

The NDIS needs a clear and transparent process for crisis management. Including:

- crisis management/ rapid response team – focussed on direct response and planning for participants

- specialised support
- access to contingency funding
- availability of specialised case management/support coordination hours

### Recommendation 6: Resourcing of Safeguards

We call on the Commonwealth government to adequately resource Independent Disability Advocacy by recognising the significant role it plays in safeguarding people with disability. Leadership Plus identifies people living with ABI as a high-risk population group requiring advocacy as a safeguarding mechanism.

The NDIS Quality and Safeguard Commission has a legislative responsibility and currently does not make full use of its enforcement powers. We believe that greater emphasis needs to be placed on timely response and proactive monitoring of provider performance to enforce compliance (see DAV, 2022, paragraph 107 and 108, p. 30-31<sup>xvi</sup>).

We also endorse the recommendation made by DAV in the submission to the Disability Royal Commission regarding adequately resourcing programs like the Community Visitors program and Independent Third Persons, embedded in the Office of Public Advocate (OPA) with legislative powers to monitor, report and investigate quality of services provided to people with disabilities (DAV, 2022, p.6<sup>xvii</sup>). These programs provide a crucial safeguard for the protection and promotion of the human rights of people with disability in Victoria and should be adopted and funded nationally.

Importantly, in the words of ***Everybody Matters*** (*State of Victoria Family Safety Victoria, 2018<sup>xviii</sup>*), our recommendations

*'shift the responsibility for inclusion from the individual to government and the service sector, so that people with lived experience of family violence [sic, acquired brain injury] will no longer carry the burden of securing their own safety, and to change the way the service sector works...'* (p. 42).

\* \* \*

Our companion submission ***Hear My Voice*** (Appendix 1) has been crucial in driving the content and complexion of this submission and should be read now. Based on four workshops with people living with ABI the report represents the Leadership Plus codesign approach.

Leadership Plus additionally endorses submissions to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability made by Disability Advocacy Network Australia (DANA, 2022<sup>xix</sup>) and Disability Advocacy Victoria (DAV, 2022<sup>xx</sup>). Further, in making this submission Leadership Plus draws attention to the structure and arguments presented in ***Everybody Matters<sup>xxi</sup>*** (2018) which forms a systemic and practice response to family violence in Victoria and which provides a strong cognate approach to reframing policy and practice upon which the DRC might choose to draw.

## Submission to the Disability Royal Commission: detailed report.

People living with Acquired Brain Injury (ABI) experience different 'injuries to their brain'. It is understood that damage to particular areas of the brain results in patterns of behaviour, challenge, and disablement. However, despite these differences Leadership Plus has over decades also observed patterns of experience that are socially determined. Leadership Plus will show in this submission how these experiences are unique to people living with ABI and what implications this has for their experience of violence and abuse.

The Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disability (DRC) has adopted a theoretical lens drawing upon human rights, disability theory, discrimination, and intersectionality in order to, '*understand the forces that shape the lives of people with disability and make recommendations for lasting change*'. As suggested by Disability Advocacy Network Australia (2022<sup>xxii</sup>)

'There is increasing recognition of the multiplier effects of intersectional disadvantage for people who have disability along with health and/or other issues that influence their well-being - for example, welfare, poverty, housing and justice related issues', (p.6).

Our aim in this submission is to demonstrate these 'unique forces' as they relate to people living with ABI.

Our contribution is vital. In Australia in 2022 over 323,000 people live with head injury, stroke or acquired brain injury<sup>xxiii</sup>.

Yet, despite an unparalleled dataset with thousands of submissions, Issues Papers and Research Reports, very little DRC data is focused upon the experience of people living with ABI<sup>xxiv</sup>. Indeed, the DRC has adopted in its work, the broad category of 'people with cognitive disability'. This effectively 'hides' the experiences of people with ABI within the experiences of a broader group of people. A belief of Leadership Plus is epitomised in some of the case studies we collected for this submission in which people living with ABI told us:

*'ABI is the least understood of disabilities' (#3)<sup>xxv</sup>*

*'And I think it's this generalist idea of disability... [It] doesn't highlight the specific needs of someone with ABI. So, there's just that lack of understanding' (#9).*

Our experience is that many people living with ABI do not have the resources, or disability and other formal and informal supports at hand, to address their unique issues as they arise. As a result, the experience of many people living with ABI includes isolation, poverty and living on the margins of survival often with no or inappropriate services and specialised supports. When people have limited financial and other resources they are limited in their choices and cannot to climb out of precarity. Reflecting on these common experiences one person in our workshops, which led to our companion volume **Hear My Voice** (Appendix 1), said this precarity was,

*'the only experience likely for people living with ABI', (WS#3)*

For those who do receive disability services and accommodation, Leadership Plus continues to be disappointed by the level of plan support and limited access to NDIS funding and by the number who receive inappropriate residential options and who have endured exclusion, frustration, time delays and ongoing requests for further information.

As a result of their experiences people living with ABI are at a greater **risk** of experiencing or being vulnerable to violence and abuse<sup>xxvi</sup>. Many of these risks are created socially by their interaction with members of the community and with disability and generic services. As a result, finding solutions needs to address these ‘social determinants of risk’

**Leadership Plus will show in this submission the evidence of risk. We will propose solutions to risk that ensures there are protective factors in place and solutions that mend the gap between risk and defending, protecting, and ensuring the human rights of people living with ABI so as to maximise the chance of keeping them safe and free from violence and abuse.**

**Below we outline the evidence we draw upon to make this case. The decision to collect different tiers of evidence driven by the voice and views of people living with ABI in *Hear My Voice!* (see Appendix 1) offered the chance to: identify the unique experience of people living with ABI; to use case studies that demonstrate detailed examples of risk; to reflect on the causes of such risk with disability advocates from around Australia; and, to interpret the findings using the experience of Leadership Plus over the years.**

The evidence used in this submission

Our submission draws on the following evidence. Leadership Plus:

- i. has four decades of engagement with people with living with ABI. It continues to provide advocacy, run peer support groups with United Brains<sup>xxvii</sup> around Victoria<sup>xxviii</sup> and continues to provide independent advocacy, personal development and capacity building to people living with ABI. This knowledge and day to day experience has driven the Leadership Plus submission.
- ii. ran four workshops with thirteen people living with ABI. The report *Hear My Voice* is submitted as an accompanying document to this submission (Appendix 1). Leadership Plus is determined and proud to make sure that the voice of people living with ABI drives our agenda and our suggestions for change.
- iii. collected and analysed eleven case studies relating to people living with ABI from individual advocates across a number of independent disability advocacy agencies in Victoria
- iv. ran a national web-based survey<sup>xxix</sup> (with support from the Disability Advocacy Network Australia) to individual advocates around Australia in relation to their work and, more specifically, to their individual advocacy work with people living with ABI.

In this submission we reference each of these data sources as appropriate. We lay out evidence including case studies, survey data and other data in light blue boxes throughout this submission. Further we ask readers to refer to the recommendations stated earlier at appropriate points.

The unique situation of risk experienced by people living with ABI

### Invisibility and Accompanying Risks

Many people living with ABI remain unheard and their disability unseen. Often, they experience ableist attitudes and systems in the community and even within disability services. Leadership Plus

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believes this invisibility increases the *risk* of violence and abuse. Moreover, much violence and abuse can go unseen and, so, people may continue to live with the threat or reality of violence and abuse in their lives.

It has already been pointed out that the DRC adopts the broad category ‘cognitive disability’ which hides the unique experience of people living with ABI. In the workshops that led to our companion submission **Hear My Voice** (Appendix 1), many participants talked of their ‘hidden disability’, a fact referenced in other submissions to the DRC (Synapse, 2022)<sup>xxx</sup>. In our workshops participants spoke of their disability as often being ‘invisible’ to the public and sometimes invisible to those who carry out assessments, to disability services, the NDIS and others. As a result of the invisibility of their disability, others make ableist assumptions. As one person put it

*‘...I’m being forced to live an able-bodied life... And I want assistance to **live the best ABI life that I can**’.*

A common view amongst participants when invited, was to express a reticence to participate in the workshops because, they had ‘screamed as loud as they can, but their voice was never heard’. This is why the name of the accompanying report of the workshop was chosen – **Hear My Voice**. Leadership Plus agrees with **Everybody Matters** (2018)<sup>xxxii</sup> that

*‘First and foremost, listening to the voices of people with lived experience from all communities helps to develop a clear vision of how inclusion should be framed’, (p.15).*

In our national survey of disability advocates we found that 86% (n=42) agreed with the statement that: ‘People living with ABI are vulnerable to violence, abuse, neglect or exploitation’. International studies have provided very strong evidence that ‘invisibility’ is a huge factor relating to the risk of experiencing violence and abuse<sup>xxxii</sup>.

Where people are unseen, cannot speak for themselves or are unheard, the risk of experiencing violence and abuse increases as argued by in the submission to the Disability Royal Commission by DAV<sup>iv</sup> (DAV, 2022, p. 23). Crucially, if people remain unseen or unheard the risk is increased because they cannot access what they need in order to protect themselves and achieve their human rights.

In **Everybody Matters** (2018)<sup>xxxiii</sup>, a response to the Royal Commission into Family Violence, it is stated that,

*‘The Royal Commission recognised that for some groups in the community family violence is less visible and less well understood by service providers and the broader community, and that their experiences are not necessarily reflected in current frameworks’ (p.22).*

Leadership Plus argues the same is true in relation to the experience of violence and abuse by people with disability. The experience of Leadership Plus is also that people living with ABI are one of the least understood of disability groups and that training and knowledge around their needs by services and professionals is currently lacking. This increases their risk of invisibility and of being vulnerable to violence and abuse.

Systems need to be in place to make sure people living with ABI do not get lost because their needs and wishes are neither heard nor seen. It is vital that each individual’s voice is heard as well as the collective voice of people living with ABI whether they are in receipt of disability services or not.

## Adaptation to a new life and associated risk factors

Subsequent to acquiring their injury and usually after a period of rehabilitation, people living with ABI have to adapt to new lives, relationships and identities. People with ABI lived life as a person without disability prior to acquiring their injury. This means they have to adapt and adjust to different lives and doing so can pose a series of unique risks others do not face. Many who go back to their lives in the community after their injury, may find their relationships with members of the public, in their family homes, with friends, in relation to jobs and so on, change substantially.

In the experience of Leadership Plus, some people living with ABI can show frustration and anger at their predicament and as a result of their disability exhibit other behaviours that do not meet the wider perceptions of social norms in the community or long held expectations held within families and by friends.

Often the systems of reliable and effective informal support with friends or family also break down as a result and this can lead to isolation and loneliness. Sometimes it is not just relationships that change but where and with whom the person lives, their employment and education.

For others who require specialist support and accommodation there is an even bigger break with their past.

These experiences of adaptation are unique to people living with ABI and influence their lives and experiences.

There is very little awareness, knowledge and understanding of these unique challenges that people living with ABI face. More information and training of the public, of family and other informal supporters is required. Disability services and support workers need to understand the complexities experienced by people living with ABI and to understand the broader systemic influences and gaps in service delivery.

Please refer to Recommendation 1 a) Specialist training,

which points to the need to understand the unique experience of people living with ABI.

## Challenges organising lives and responding with crucial decisions and the attendant risks

People living with ABI often struggle with processing and absorbing information and making decisions. Effective, independent decision support is crucial. Often, not being able to engage, make and communicate decisions will put people living with ABI at risk in a number of ways as shown below.

People with ABI know the lives they want to live. However:

- Many have little or no opportunity to explore and understand their options and needs, with little time and support to understand and make decisions.
- People living with ABI may give the impression they understand when they do not
- Many seem to change their views
- Many feel rejected, misunderstood and ignored
- Without effective support people living with ABI are at risk of their entitlements being missed or denied, due to them not responding to essential correspondence.

### Evidence

Case studies:

*'he cannot organise a thing in their life... doesn't remember what you said, you know, 10 minutes ago or yesterday or whatever' (#7),*

*'There's so much going on in his life...it's not explained to him properly and he's not fully involved in decision making. So he becomes so frustrated and angry at people... knowledge and knowledge of consequence...needs to be consistent and persistent' (#9),*

*'...he struggles to process large amounts of information... And I think just holds on to certain aspects of it. So yeah, probably it's in the moment' (#9).*

Our national survey of disability advocates found:

- 73% (n=36) agreed with the statement that 'making decisions, initiating and/or responding to formal correspondence places people living with ABI at a distinct disadvantage'.
- 65% (n=32) agreed that people living with ABI 'seem to have periods of clarity and confusion more than other people', whilst
- 80% (n=71) agreed people living with ABI 'need more help just organising their lives' and
- 74% (n=36) agreed that 'people living with ABI often forget what was decided and do not follow the decisions previously agreed.'

People living with ABI therefore require consistent, reliable and safe support from those without any conflict of interest to ensure that at all times they have information upon which to make decisions and can respond when required to do so. In their submission to the Disability Royal Commission Disability Advocacy Victoria (DAV, 2022) <sup>xxxiv</sup> have also pointed out in relation to people with disability that

*'The length and complexity of the formal complaints process were a barrier... The complex communications, form-filling, as well as the adversarial nature of the process, disempowers people with a disability unless they have an advocate supporting them. Such disempowerment can result in withdrawal' (DAV, 2022 p.5).*

This complexity is particularly challenging for people living with ABI as well as for advocates<sup>xxxv</sup>.

Providing specialist support therefore requires specific knowledge of supporting people living with ABI as it relates to the NDIS, NDIS providers, Health, hospitals and medical providers, the Justice system and broader community service sector supports.

Please refer to Recommendation 1 a) and b): Specialist Support

Given the evidence on processing information many people living with ABI will require additional targeted support for decision-making,

Please refer to Recommendation 2: Decision Support.

Given system complexity, adversarial complaints and other processes, as well as troubles processing and then pursuing decisions people living with ABI may require independent disability advocacy to protect, defend and ensure their rights if there are no other appropriate services and supports helping them to do so.

Please refer to Recommendation 6: Resourcing of safeguards.



## Risks associated with too few people accessing the NDIS<sup>xxxvi</sup> and services they need

The lack of services and supports or, indeed, not receiving any services can leave people living with ABI at risks which are unique to them and, as a result, can make them more vulnerable to violence and abuse.

Those involved in NDIS Planning and assessment do not understand the functional impact of ABI <sup>xxxvii</sup>. Certainly, the NDIS does not succeed in supporting sufficient numbers of people living with ABI independently in the community. Without accessing disability specific services those living independently in the community use generic housing, education, Centrelink and other community services. Many find these ableist and inappropriate to their needs. When inadequate support is combined with difficulties managing and organising everyday lives, catastrophic outcomes can follow, resulting in a greater risk of violence and abuse.

For example:

- Many people could not understand what to do to apply to the NDIS
- Some found the NDIS forms impossible to understand and there is little or no formal support available to assist with application.
- Despite being at risk of violence and abuse many people living with ABI living independently in the community do not access the NDIS.
- Many found they were denied access to the NDIS.
- When the NDIS started many peer support groups in the community were shut down. People do not understand the Information, Linkages and Capacity building or see its relevance to them.
- Without access to disability specific support people rely on generalist housing agencies, employment and income support services which do not understand the functional impact of ABI.

There is a vital need for the NDIS to re-examine what is 'reasonable and necessary' support for people living with ABI living independently in the community. Such people must not remain hidden and subject to increased risk and their needs understood.

Please refer to Recommendation 1 a): Specialist Support

When sufficient and appropriate specialist support is **not** available to people living with ABI the risk of violence and abuse increases because it becomes easier for: -

- some people to make decisions for the person. They claim the person cannot make their own decisions and/or speak for themselves
- some people to ignore the person's choices
- physical and emotional pressure or abuse to be used to replace the person's decisions
- people living with ABI to find it too hard to complain and to know to whom they should complain.

These experiences take place where there are close relationships such as in families or with partners. They happen because some people use their power and influence over the person's rights. Since many of these relationships are not visible to others, the person living with ABI is at a higher risk of violence and abuse.

#### **Evidence:**

##### Case studies:

*'they [family] just did not believe this person was cognitively able to make their own decisions'... So this person couldn't make their own decision about wanting to live independently' (#11),*

*'...in giving that [complaint] to the facility and the unit manager saying "no, he does not have capacity to make his own decisions and to report things accurately"...even after going to the extreme of having yet another assessment by a neuropsych, the manager of the unit still maintained that this assessment was incorrect and that*

*"Well, I disagree with that assessment" (#7)*

*'...it's actually resorted to this person needing to get an intervention order, a family violence intervention order, [from a relative] to stop their harassment' (Anon)*

When a person has no support to make decisions, does not or cannot access disability services and is not seen or heard they are likely to be unseen and/or become isolated. Many find themselves in difficulty and are fearful, overwhelmed and unable to achieve their life goals. Many do not know how to complain and do not get access to disability advocacy or other specialised support. Moreover, in some cases others can speak for them or suggest they cannot make their own decisions. The *risk* of violence and abuse in these circumstances is much higher.

Without disability advocacy as well as specialised support, people living with ABI are more at risk of (living with) violence and abuse, with no way to complain or change their circumstances.

[Please refer to Recommendation 6: Resourcing of Safeguards](#)

Leadership Plus suggests the need for some way of ensuring greater visibility of non-NDIS participants living with ABI and increased advocacy targeted at preserving their human rights. Crisis management to ensure those at risk of violence and abuse have dedicated and targeted support when they need it as well as a means of preventing situations from becoming crises is also vital.

[Please refer to Recommendation 5: Crisis Management](#)

## The experience of people living with ABI

The DRC have focused upon a number of contexts or life domains such as education health, restrictive practices and the criminal justice system<sup>xxxviii</sup> in relation to the experience of people with disability. In *Disability in Australia: shadows struggles and success* the DRC found that safety depends on environments and interaction with people and systems<sup>xxxix</sup>. Using our data, we explore below

these issues for people living with ABI in relation to ‘community inclusion’, ‘housing’, ‘achieving a regular income’ and ‘the criminal justice system’.

### Risks Resulting from Community Exclusion

Many people living with ABI independently in the community experience higher ‘levels of prejudice, paternalism, stigma and marginalisation’ which increase the risk of them experiencing violence and abuse<sup>xi</sup>. For those people living with ABI independently in the community:

- Some find their social networks broken when they move from rehabilitation and others that these networks reduce over time. Many feel stigma and shame when they re-enter the community.
- Some try hard to make new friends. They can experience rejection or find themselves in risky situations which lead to violence and abuse
- They experience ableist attitudes in the community
- Some choose to isolate from others in the community
- There are cases where family relationships have changed and may involve violence and abuse<sup>xii</sup>
- Some become frustrated and act with behaviours that alienate others<sup>xiii</sup>
- Many end up with limited informal supports in the community and amongst friends and family<sup>xiiii</sup>

#### Evidence:

##### Case studies:

*‘sometimes it’s really hard to join them because of the shame or the self stigma or the internalized ableism. All that stuff that you’ve internalised from society’s attitudes which prevents you from joining the community, and that can take years’ (WS#1).*

*‘a lot of people also think that acquired brain injury is the fault of the person who has the acquired brain injury’ (WS#3).*

*Being acceptable to society again, because after the brain injury I all of a sudden...I felt like I was an alien almost and in my search for acceptance, I would offer myself to men’ (WS#4)*

*‘I think scared to tell anyone those because of what might happen... I chose to isolate myself which is not helpful, but it felt like the safest thing to do and I look back and I’m so sad’, (WS#4).*

*‘Because basically the people that are around me are just so not worth it, so I chose to isolate myself...’ (WS#4)*

##### Case study:

*‘gets mixed up on things. He’s angry about the loss of, you know, his ability to have a partner and you know, he doesn’t have a lot of friends. And so he’s isolated and... desperately wants friends and loves, you know, socialising like’ (#1)*

##### Our national Survey found:

- 73% (n=41) of the sample felt that ‘people living with ABI are vulnerable to violence, abuse, neglect or exploitation because of their isolation’ (with just one person disagreeing with this comment).
- 61% (n=32) agreed that ‘People living with ABI are similarly vulnerable because of changes in their relationships with family after acquiring their disability’.

Given the above examples of lost or strained social networks participants also talked in the **Hear My Voice** workshops about the defunding of peer support groups<sup>xliv</sup> after implementation of the NDIS,

*‘...it’s also been really traumatising for that to happen. But it is because of the NDIS and the way that it sees people as individuals and doesn’t believe that, you know, we learned through community, so it’s shut down through the funding structure...all the drop in or the community disability spaces that existed of all so many of them have disappeared and quite violently disappeared by just kicking people out’ (WS #3).*

This produced further isolation<sup>xlv</sup>.

Peer support and self-advocacy groups for people living with ABI make an invaluable contribution to 'constructing competent selves; tempering the threat of loss and impairment; resisting infantilisation and deligitimisation; and asserting collective...identity'<sup>xlvi</sup>. It is vital that more are funded across the community.

Please refer to Recommendation 4: Peer Support and Self-advocacy

People living with ABI can also become isolated if they live in inappropriate accommodation. People living in inappropriate settings were found:

- To be lonely and isolated and waiting for meaningful interaction with others
- To lose friends in the community as well as reliable informal support for community inclusion
- To suffering boredom and depression

**Evidence:**

Case studies

Of a woman in aged care

*'she just sits everyday waiting to have interactions with people. Yeah, and she says, you know, she feels depressed and she wants to go outside, and she just sits there staring at a television waiting for someone to walk in the door' (#3),*

*'His parents and brother... all deceased and he didn't have a lot of friends. Wow. And the longer he lived in aged care, the more isolated he became especially as most of the other residents had dementia (#7).*

And the closure of peer support

*'...it's also been really traumatising for that to happen. But it is because of the NDIS and the way that it sees people as individuals and doesn't believe that, you know, we learned through community, so it's shut down through the funding structure...all the drop in or the community disability spaces that existed of all so many of them have disappeared and quite violently disappeared by just kicking people out' (WS #3).*

There is an urgent need to address inappropriate accommodation as discussed further below.

Please refer to Recommendation 3: Human Rights

## The Risks of Housing Precarity for people living independently in the community

After rehabilitation significant percentages of people with ABI have a change in their living situation<sup>xlvii</sup> that can increase the risk of violence and abuse. The type of accommodation in which a person lives has impacts on levels of community integration and participation and isolation as well as other personal outcomes<sup>xlviii</sup>. People living with ABI independently in the community are likely to experience housing precarity, given the wider housing availability and affordability issues in Victoria and elsewhere around Australia<sup>xlix</sup>.

Leadership Plus has found varied experiences of accommodation some of which were a problem. Many people have difficulties in the relationships with those with whom they live<sup>l</sup>, some of which leads to family violence<sup>li</sup>:

- Many people living in inappropriate accommodation such as boarding houses or SRS<sup>lii</sup> or mental health settings, experience verbal and other forms of abuse
- There is a greater likelihood of homelessness<sup>liii</sup> or being moved, to places the person does not choose
- There is a lack of housing security with fixed or limited tenure which leads to precarity and recurring difficulties finding new housing<sup>liv</sup>.

Too many people living with ABI living in the community experience housing precarity in the competitive rental market and have low levels of security of tenure. Australia is facing a housing crisis with homelessness at record breaking levels.

Some find themselves homeless or living in boarding houses or SRS. The risk of violence and abuse in these circumstances is high especially where the person does not have the resources to change their lives, finds it hard to make decisions<sup>lv</sup>, or does not have access to advocacy and other specialised supports to address their living situation.

### Evidence:

#### Case studies:

*'...their support coordinator...believed this person had communicated to them that they wanted to move into their own place and live independently.... It was urgent because the family was applying for a Guardianship order to be put in place. So this person wouldn't be able to make their own decision about wanting to live independently' (#11).*

An Aboriginal woman was fearful of neighbours who were using drugs. She was moved to more accessible accommodation but was then subject to racism and threats from neighbours and had a rat infestation. The advocate sought unsuccessfully to change her housing again saying. *'Taking the matter to the next level, VCAT... would be about four years advocacy involvement' (#2),*

*'...she remained in a unit that her parents had owned jointly until they could no longer afford it... so she had to move out...that was a crisis...ended up running off and holding a weapon. And police found her...So that the one of the issues...all along that they don't see her as specialist disability accommodation', (#1)*

*'He was borrowing money from people in order to pay his rent... And also because he couldn't always remember who we borrowed them from... So he sort of had a sense of shame. So he moved to a different [community group]' (#12).* This person lost their new rental, was 'found wandering' was picked up by the police who found a place in a mental health unit and then on to a State registered Service.

*'I actually did experience homelessness in the first few years after my brain injury...because of the rental market. And I tried to do share housing and I had some appalling experience...I had to take an intervention order out against the house mate who was being violent...and that was horrific because the justice system is not set up for people living with ABI and it just continued for many years and it was really awful' (WS#3).*

*'...when you're going for a rental and your income is only from Centrelink, for example, that's not deemed as an appropriate income for rent' (WS#2).*

#### Our National disability advocate survey found:

57% (n=28) felt that 'people living with ABI are more likely to become homeless than other people with disability'

#### Workshop with people living with ABI:

Participants observed that if they went for a rental and the Landlord identified them as a person living with ABI that they were rejected out of hand. A result is that they live in constant fear of losing their home.

Housing precarity leads to higher levels of violence and abuse and there is a real need to defend, protect and ensure human rights in this area. As a result, the likelihood of violence and abuse is underreported. Many people living with ABI continue to endure violence and abuse as a result. This leads to our primary recommendation around housing rights.

Please refer to Recommendation 3: Human Rights

Leadership Plus would like it to be noted that the risk of violence and abuse for people living with ABI independently in the community is: higher than for many people with disability but proportionately greater than for the population as a whole; that their unique challenges in processing information is a contributory factor where there is no specialised support available; that many do not access disability and other services and remain hidden and even more vulnerable to violence and abuse; that many are forced into accommodation they do not choose; and, that many live in fear of housing precarity. People living with ABI simply do not have the funds or other resources available to them to allow them to control their life choices. These experiences mean that in many cases human rights cannot be protected, defended nor ensured without both decision support and independent disability advocacy. As such additional recommendations need to be in place also:

Please refer to Recommendation 2: Decision Support

And Recommendation 6: Resourcing of Safeguards

This often leaves them in housing crisis, experiencing cycles of homelessness and at risk of or, indeed, continuing to endure violence and abuse’.

Please refer to Recommendation 5: Crisis Management

## Risks associated with Housing issues for people living in ABI in funded accommodation

Leadership Plus continues to see people living with ABI discharged from rehabilitation to inappropriate accommodation<sup>vi</sup> such as residential aged care or nursing home settings. Many become isolated in such settings and may suffer neglect as well as violence and abuse. The risks are high because:

- Many young people living with ABI are still moved into aged care,
- The service and support response in aged care and nursing homes is not sufficiently specialised and is often insufficient<sup>vii</sup>
- In these settings, support for personal development, community inclusion and other chosen outcomes is inadequate
- Research reports feelings of 'broken selves' and 'stagnated lives' of 'confinement', 'disempowerment', 'emptiness' and 'hope for greater autonomy'<sup>viii</sup>.
- The NDIS often resists providing access based on the responsibility being taken by aged care or health services.

Leadership Plus is also aware of an increase in cases of neglect and other forms of violence and abuse in these settings. They observe:

- Significant waiting times for a move to Specialist Disability Accommodation
- Long battles with the NDIA regarding Specialist Disability Accommodation and Supported Independent Living that often go to the AAT<sup>lix</sup>

### Evidence:

#### Case studies:

*'...a 48 year old man who had a catastrophic brain injury about six years ago.... was moved to an aged care facility in <<place>>...even though he was only in his 40s... he was in the dementia wing, the NDIS would not come to the party. They just kept saying no. He's in aged care. That's their responsibility', (#6).*

*After having a stroke, a woman in her fifties '...was discharged to a nursing home. She wasn't given any sort of adequate supports for rehabilitation....' (#3).*

*After rehab, for one man, ' the support coordinator had already sourced a self-contained accessible unit at the rear of the group home which the accommodation provider had held for...about six months. But the NDIS knocked that back that ..and said "no". They asked us to look at all options including private rental.. so not affordable, unlikely to be accessible...' (#7).*

*A 16 year old under child protection was placed in residential care 'and that's something that he's explicitly stated that he doesn't want to be in. He wants to have a relationship with his family and he ...talks about wanting to make the right decision.. he's not getting the kind of support that he needs to help practice those skills and develop' (anon).*

*'...he needed one to one for 10 hours a day...NDIS funded him for six hours... **But in between that is basically neglected...** [his relative] was spending about 28 hours a week in the facility basically assisting the staff... but was trying to run a business.' (#6).*

*'very worried about the standard of care in the aged care facility [and in time] the resident got a life threatening infection...of the pressure wounds on his right leg' (#7).*

*'...she's had to be hospitalised. And we think that that it was a result of her having inadequate supports. Yep. And that the information before the NDIS and now also the Administrative Appeals Tribunal foreshadow that accident was a real possibility. NDIS said, you can accept this offer and we'll settle the agreement. Otherwise we're taking it away. So it's incredibly stressful for the woman' (#3). The NDIA instructed the advocate to withdraw the original application after the accident as the situation was "different". But the hospital she was in said they would not discharge her unless there was sufficient support and the support coordinator followed all this up. 'She's just gonna be completely disempowered because we're just here waiting for the agency. The hospital's waiting for the agency... Yeah. It's very, very, very difficult' (#3).*

- As people wait to move, they continue to experience issues including neglect and violence and abuse.

Once again, our primary recommendation around housing relates to human rights.

Please refer to Recommendations: 3: Human Rights

The risk of violence and abuse is much higher for people living with ABI when they live in inappropriate settings. Homelessness, boarding houses and SRSs are places with higher risks and without specialised support many people living independently in the community endure violence and abuse. Much of this remains unseen and not addressed since people often do not know how to complain and do not have support nor resources to address these issues.

Discharge planning which places people in residential aged care, nursing home or crisis care increase the risk of neglect given the lower levels of specialised support provided. Resistance by the NDIS to provide disability support and access to SDA continue. The NDIS seems to employ inertia and challenges the right to SDA which is stressful, takes time and leaves people unsafe. As can be seen the evidence Leadership Plus has presented encompasses many of further recommendations set out at the beginning of this submission.

Please refer to Recommendations 2: Decision support

And Recommendation 5. Crisis Management

And Recommendation 6. Resourcing of safeguards

As Leadership Plus will assert shortly, as there are multiplier effects when a number of risks are experienced together, there are also multiplier effects when the collected recommendations made in our submission are placed together to provide a systemic response to violence and abuse. As a result, our recommendations are linked and interdependent. They cannot be adopted in part if they are to have full effect.



## Risks associated with low income

Having an income is important to us all. Having income extends our opportunities to pursue our life choices. Many people living with ABI had employment prior to their injury and many did not return to their previous work. So, many people with ABI living independently in the community are very eager to access training, education and employment. However, living without a regular income can lead to impoverishment, to isolation and to further risks of violence and abuse.

The Leadership Plus evidence shows:

- Difficulties getting jobs in the competitive job market and exploitation and abuse in the workplace<sup>lx</sup>
- That Job Network and disability employment providers do not meet the employment needs of people living with ABI
- That many employers do not understand reasonable accommodation to support continued employment<sup>lxi</sup>

In relation to training and education Leadership Plus has found that:

- education and training is not available or designed to support people living with ABI

In relation to benefits we found:

- low income and reliance on benefits, particularly the DSP
- People scared of losing the DSP which became a disincentive to moving into work

### Evidence:

#### Case studies:

*'Like going to job network providers and everything. I've been to a number of job network providers who like to portray themselves as, "yes, we're disability focused...and they don't do anything. There is nothing beneficial that I've ever gotten from any of them. But I was forced by Centrelink to go...Every job that I've found, I found myself' (WS#1).*

*'Disability Employment services also err on the side of stupid jobs like warehouse or factory floor options. This is what I went through when I was looking for work in the early years of my injury. They do not acknowledge the person's prior skills' (WS#1).*

*'...trying to be more employable, like education and training is part of that. And I just wanted to relate that you know that that's really, really often really inaccessible' (WS#2).*

*'... but even the disability liaison unit were trying to get me to hide some of my disabilities, not list them because they said that some of them was more stigmatising than others' (WS#2)*

*'How do you teach these people [people living with ABI]?...They're not capable of being taught. Maybe their [education and training centres] discrimination is so deeply, deeply ingrained', (WS#2).*

*'I got kicked off the DSP because Centrelink kept saying to me that MS has been cured' (WS#3)*

*'came off DSP when they received a compensation payment, but when that was exhausted...it took another ten years to get back on it' (WS#3).*

As a result of the factors above people living with ABI have a lack of disposable income and savings to support them to make and pursue preferred life choices. Poverty leads to precarity and fear for the future. These factors can lead to further isolation with vulnerability and greater risk of violence and abuse. These circumstances surrounding income are known. Systems that do not address these issues are therefore perpetuating institutionalised violence and abuse against people living with ABI.

Evidence also shows that employment outcomes get worse over the years after their injury<sup>lxii</sup> and that in employment people can be exploited<sup>lxiii</sup>. Yet, with the right employment supports<sup>lxiv</sup> it has also been shown that better outcomes can be achieved<sup>lxv</sup>. However, without the right service and specialised supports there is a gap that many cannot bridge.

Please refer to Recommendation 1 a and b – Specialist Support

Systems of training, education and support to find employment need adaptation to meet the support needs of people living with ABI living in independent settings without current disability support. Benefits systems must be arranged to motivate people to find and *keep* work. Employer-friendly policies are needed to maintain employment. A reasonable standard of living cannot be achieved by many people living with ABI and the systems which perpetuate this experience are inadvertently contributing to systemic violence and abuse against people living with ABI. Our primary recommendation therefore relates to meeting their economic rights.

Please refer to Recommendation 3: Human Rights

## Risk as a result of higher levels of engagement with the criminal justice system

There is an over-representation of people living with ABI in the prison system<sup>lxvi</sup>. It is reported that 42% of male and 33% of female prisoner live with an ABI<sup>lxvii</sup>, a massive proportion. It has also been found that people living with ABI 'found it hard to achieve justice based on discriminatory behaviour by police and others'<sup>lxviii</sup>. It is all too easy for people living with ABI to end up in situations of 'heavy embroilment'<sup>lxix</sup> with the youth or adult criminal justice system given their 'cumulative adversity'<sup>lxx</sup>. The risks are disproportionately high in relation to violence and abuse where people with ABI are involved with varying parts of the criminal justice system.

The Leadership Plus evidence shows that:

- Many people living with ABI fear ending up in the criminal justice system, in courts and in jail.
- Some fear incarceration in psychiatric settings
- Many have had high levels of interaction with law enforcement and the criminal justice system
- significant support is needed from advocates in liaising with police<sup>lxxi</sup> and support in court<sup>lxxii</sup>.

### **Evidence:**

*In our national survey of disability advocates:*

49% (n=24) of participants agreed that 'people living with ABI are more likely than other people with disability to end up in the criminal justice system'

*In our Workshops:*

*'one of my fears for many, many, many years has been the fear of incarceration because I felt like my behaviours would, you know, could be really problematic with police and with professionals' (WS #4).*

*'In medical systems and fear of being locked up in a psych unit and fears of being locked up in prison for what I might do and having murderous thoughts'. (WS #4)*

*'Just my attempts to try and clear my name twice and ended up in me getting a good behaviour bond twice which was a really scary thing And I really didn't have to do very much to get that' (WS#4).*

*Case studies:*

*'I did a lot of work with the police around them understanding that he shouldn't be served in the hospital because they often served them as they're discharged...And it's just such a trigger for him and he wouldn't understand' (anon)*

People living with ABI fear incarceration in prison or mental health settings. Many are traumatised by their experiences of incarceration where they experience violence and abuse. Prison and engagement with the criminal justice system can lead to trauma, interruption to their lives and difficulties re-entering the community. These circumstances are also a huge draw on the public purse. There are significant efforts to address the issues of people with ABI experiencing a revolving door into prison<sup>lxxiii</sup>. It is also important to address issues prior to that and for people to have sufficient advocacy and specialised support to stay in the community.

Our primary recommendation in this area suggests more support and advocacy are required to support the person in the community, with police and across the criminal justice system.

**Please refer to Recommendation 6: Resourcing of Safeguards**

The experience of people with ABI in the criminal justice system is unique and should be understood by those seeking to deliver specialised support. Given the complexity of their engagement with these systems specialist case management using a single point of contact is also important

Please refer to Recommendation 1 c: Specialist Support.

Given difficulties in processing information decision support is also an important factor for many people navigating through the complex criminal justice system in ways that meet Articles 12 and 13 of the Convention on the Rights of Persons with Disabilities: Equal recognition before the law and access to justice. Further having informal support networks can also support and help the person with their confidence in these systems and with speaking up and raising the alarm when they can find no resolution to the problems they face at any point in time. As such further recommendations Leadership Plus makes are required to reduce the risk of violence and abuse.

Please refer to Recommendation 2: Decision Support

And Recommendation 3: Human Rights

And Recommendation 4: Peer Support and Self-advocacy

Mending the gap between risk of violence and abuse and sufficient and appropriate support

Leadership Plus has demonstrated many issues for people living with acquired brain injuries that increase the risk of them experiencing violence and abuse, for example:

- policy or, indeed lack of policy and access to services, can create poverty, isolation and increase the risk of violence and abuse for people living with ABI.
- Living impoverished lives creates isolation, stress and health issues. Without resources or specialised support people living with ABI cannot make choices to change their lives and they live in constant fear of 'going under'.
- Isolation from services, from informal supports and from the wider community is linked to a greater risk of experiencing violence and abuse
- If there are no specialist supports for navigating bureaucratic systems and decision support, the risk of violence and abuse increases.

In this submission to the DRC, we have produced a list of issues. But it is vital to note that when several of these are *experienced together* the risk of violence and abuse increases exponentially. Taken together the cumulative effect of our recommendations have a similar multiplier effect in addressing the risks of violence and abuse we have outlined in this submission.

It is also vital to note that the issues experienced by people living with ABI are socially produced and reflect policies and practice that are at present contributing to their experience and, as a result contributing to violence and abuse. Socially produced problems can be changed by socially produced solutions.

Below Leadership Plus uses further data collected for this submission, to address how to reduce the risk of violence and abuse to people living with ABI. As we proceed, we shall set out further key recommendations for change.

## Decision Support

Please refer to Recommendation 2: Decision Support

Many people living with ABI need support to make choices and decisions, but they do not receive that support.

Leadership Plus has experienced Guardians and State Trustees who resist the person's will and preference, something also found by others<sup>lxxiv</sup>. This leads to a greater risk that others can ignore their will and preference.

Leadership has found that:

- For many people living with ABI it takes a crisis and traumatic life event before they become known to advocacy agencies. This is destructive and costly.
- To ensure the person's will and preference it is vital to get to know the person and to understand their life preferences
- Specialised support for decision-making is crucial to many people living with ABI.

Leadership Plus is in agreement with the DRC's proposals around the implementation of co-designed decision support and Guardianship reforms<sup>lxxv</sup>. However, we also recommend specific attention be paid to people living with ABI and, especially those who do not currently qualify for disability services and supports. We also suggest careful consideration from amongst many competing models of decision support<sup>lxxvi</sup>.

### Evidence:

*In our national survey of disability advocates:*

80% (n=71) agreed people living with ABI 'need more help just organising their lives' and

74% (n=36) agreed that 'people living with ABI often forget what was decided and do not follow the decisions previously agreed.

73% (n=36) agreed with the statement that 'making decisions, initiating and/or responding to formal correspondence places people living with ABI at a distinct disadvantage'.

Further, nearly 80% (n=39) agreed that 'people living with ABI are more likely to experience fresh challenges and issues over time that require an ongoing advocacy input'.

### Case studies:

*'obviously I'm his advocate, but really I do a lot of crisis case management in a way and just respond to I feel a lot like I'm putting out fires a lot of the time because things because he hasn't got really good support' (#1)*

*'It obviously takes time for us to build rapport... very slow communication... preparing them to understand what this VCAT hearing was... how they could participate, what their rights were doing this... And then and then ultimately supporting them at the hearing as well' (#11)*

*'There's so much going on in his life that he doesn't... Understand because it's not explained to him properly and he's not fully involved in decision making' (#9)*

## Responsive services, complexity and case coordination

When Leadership Plus first becomes aware of an issue for a person living with ABI it is often already at the point of crisis, with all avenues of support already exhausted.

In our experience, resolving the issues inevitably means disability advocates:

- are required to work with and coordinate across number of agencies and service systems
- often playing a coordination or case management role in order to progress advocacy issues and achieve advocacy outcomes
- addressing more than one issue at a time
- using decision support to achieve understanding and decision-making.
- being required over a period of time to understand and support the person's will and preference

### Evidence:

#### Case studies:

In one case study the person was in contact with a huge number of services and had: acquired his injury through an assault; was a refugee; had experienced abuse in a number of housing situations, had his money stolen, been arrested; placed on a Financial Order; amongst other things. The breadth and number of organisations involved was vast.

*'you know, pursue all the case management and organizing contacts and people and you know, informing others and so on.'* (#1)

*'it's been very it's been complex, very complex. I'm working on this person's issues and I've been working with them for a long time'* (#4).

*'Can nurse, OT, wound nurse write a report and so it went on...when he finally accessed the SDA the NDIS billable hours had been exhausted so the support coordinator worked for free... she didn't tell her employer...The number of support systems intersecting and not only failing to uphold previous human rights, but also failing to provide adequate care and support. So that's neglect'* (#7)

*'Yeah, I think it is. I think it's a long term advocacy called **complex violence**. It's that sort of model where you hope that someone would be able to be referred to a **complex case manager**, you know ... **because they never picked him up'*** (#1)

*'so I think my role has been challenging because there's **an intersection of lots of different systems...** who's got responsibilities...trying to make sure that his voice is heard... negotiate... his right to have a say in these decisions, advocate for NDIS...advocate for funding to get supported accommodation. Yeah, it's a very complex'* (#9)

Earlier we also spoke of crisis responses being far too slow. Mechanisms need to be in place with rapid response times to ensure dedicated and targeted support and advocacy are readily available to those at higher risk of experiencing violence and abuse.

Please refer to Recommendation 5: Crisis management.

The NDIS Quality and Safeguards Commission has legislative responsibility in this respect but does not make full use of its enforcement powers and needs reform.

The number and complexity of agencies involved for disability advocates in addressing issues and crises is so great as to defeat the best efforts of many people living with ABI. It is necessary to have

in place a comprehensive case coordination or case management approach. Support coordinators or support coordination can be essential in this respect.

Please refer to Recommendation 1 Specialist Support, b: Specialist ABI case management.

Disability advocacy is vital to ensure the person's choices are pursued and to ensure through speaking on behalf of the person that their human rights are defended, protected and ensured. Further, Disability Advocacy Victoria (DAV)<sup>lxvii</sup> recommends resourcing for Community Visitors and Independent Third Persons initiatives embedded in Offices of the Public Advocate to provide further checks in the system. They recommend more powers for the public advocates to monitor, report and investigate quality services.

Please refer to Recommendation 6: Resourcing of Safeguards.

Ensuring safeguard systems with mechanisms for enforcement are in place, a crisis response system, specialised supports and a single point of contact through disability advocacy agencies will produce a much stronger system designed for people living with ABI amongst others who Leadership Plus sees as being most vulnerable, so as to protect them against violence and abuse.

## Disability advocacy sector needs

Leadership Plus has shown how disability advocacy is vital to support people living with ABI. However, our data and our experience highlights issues faced by disability advocacy agencies. The issues relate to the type of advocacy required for people living with ABI as well as to current sector capacity.

In relation to delivering individual advocacy for people living with ABI Leadership Plus found:

- Individual advocates report a long and complex advocacy input and a long-time building trust and establishing their will and preference.
- Ongoing issues challenge the 'single issue' advocacy principles since, all too often, one critical issue follows another
- Advocacy issues taking up more time than for other people with disability
- Most people living with ABI needing advocacy support for NDIS Appeals and reviews
- That if disability advocacy is funded by a dollar figure per case, then some cases including for people living with ABI cost more
- The funding for individual advocacy is not sufficient to cover all demands and, in particular, the needs of people living with ABI.

### Evidence

*Our national advocate survey found:*

*75% agreed the advocacy input for People with Acquired Brain Injury is usually long and involves a complex series of issues.*

*80% agreed People with ABI are more likely to experience fresh challenges and issues over time that require an ongoing advocacy input*

*64% agreed that The advocacy input for People with Acquired Brain Injury takes, on average, a longer period of time than advocacy issues for other people with disability.*

*79% agreed that People with ABI generally need individual advocacy support for initiating NDIS reviews and Appeals or for making complaints about the services they do receive.*

*Case Studies:*

*Sometimes it crosses over to the next issue the moment it's closed off... we technically should be putting them back on our wait list, putting them back through intake and putting it... But it just doesn't work like that in reality... . It is a leads back to this idea of, you know, crisis support' (#11)*

*'So yeah, three years... And I was only one of a big team that was looking out for this man' (#7).*

There is a need to increase the funding levels for individual advocacy to support demand by people living with ABI and, in doing so, to offer protection from violence and abuse as well as the pursuit of justice in cases where their human rights have been infringed. As argued in the Disability Advocacy Network Australia submission, 'Independent disability advocacy strengthens people's capacity to manage their lives and reduces the call on government agencies', (DANA, 2022, p.2)<sup>lxxviii</sup>.

Please refer to Recommendation 6: Resourcing and safeguards.

Yet, 'Disability advocacy is funded through a patchwork of Commonwealth and state and territory government programs and contractual arrangements that are fragmented and uncoordinated. Commonwealth disability advocacy funding has not kept pace with increased demand and advocacy organisations are inadequately resourced to respond to all people who need advocacy' (ibid: p.9).



It is vital to recognise the need for ongoing individual advocacy support and to recognise such advocacy cases in relation to people living with ABI can cost more to deliver. DAV (2022)<sup>lxxxix</sup> in their response to the Disability Royal Commission suggest that,

*'As cases become more complex, disability advocacy organisations are having to limit access to their services, and this will have an impact on their capacity to assist those reporting violence and abuse' (DAV, 2022, p.5).*

This complexity seems to go hand in hand with disability advocacy provided to people living with ABI. Further, non-NDIS-related issues also require additional funding given the unique challenges experienced by non-NDIS people living with acquired brain injury in the community.

Leadership Plus also believes self-advocacy is vital also. As argued by Disability Advocacy Network Australia<sup>lxxx</sup>

*'Self-advocacy can be very empowering for individuals in asserting their rights and maintaining safety' (DANA, 2022, p.4)<sup>lxxxix</sup>.*

The need for more peer support and self-advocacy remains urgent also.

[Please refer to Recommendation 4: Peer support and self-advocacy](#)

## Final Point

In this submission to the DRC Leadership plus has shown the unique experiences of people living with ABI. We have shown the gaps that are produced, which lead to the risk and experience of violence and abuse. We have also proposed some solutions, key dimensions of which are set out in our recommendations at the start of this submission.

Leadership Plus, along with many other agencies and people with disability have waited for decades for the chance to address the issue of violence and abuse which have remained recalcitrant to change despite systems change, and ongoing tinkering around disability policies and practices over the years. Given these failures, our conclusion is that new systems need to be put in place to effect change. But this cannot be done in a piecemeal fashion anymore. We cannot wait another generation for another Royal Commission before we have the chance to ask for the necessary changes.

We have asserted that there is a multiplier effect as the number of risks increase leading to greater likelihood of people living with ABI experiencing violence and abuse. Vivaly a similar cumulative gain can be achieved when ALL of our recommendations are implemented. Choosing between these recommendations will not achieve the desired reduction in violence and abuse experienced by people living with ABI.

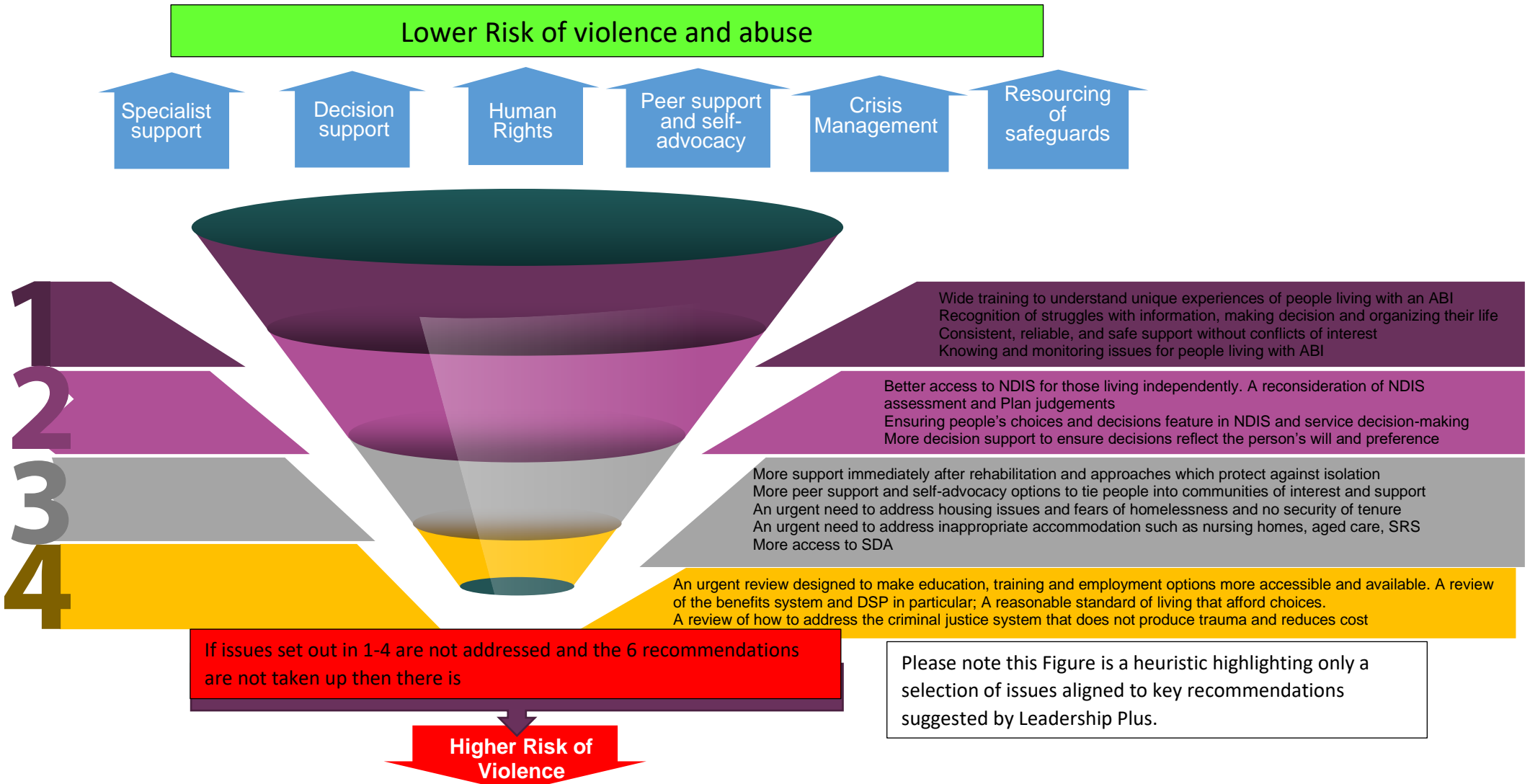
Reiterating the words of ***Everybody Matters*** (2018), our recommendations therefore

*'shift the responsibility for inclusion from the individual to government and the service sector, so that people with lived experience of family violence [sic, acquired brain injury, violence and abuse] will no longer carry the burden of securing their own safety, and to change the way the service sector works...' (p. 42).'*

Socially constructed systems can deliver socially constructed changes which challenge systemic failure and the failure of systems to adapt in ways that protect our fellow citizens living with acquired brain injury.

Figure 1 below provides a heuristic with a summary of our findings.

**Figure 1:** Showing what increases the risk of Violence and what supports human rights and safety for people living with acquired Brain Injury.



# Appendix 1

## ***Hear My Voice***

## Endnotes

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- <sup>i</sup> The State of Victoria (Family Safety Victoria) (2018) *Everybody Matters: Inclusion and Equity Statement* Melbourne: Treasury Place. Available at: <https://www.vic.gov.au/everybody-matters-inclusion-and-equity-statement>
- <sup>ii</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>iii</sup> DANA (Disability Advocacy Network Australia) (2022) *DANA Submission: Independent Disability Advocacy*, Draft, November. DANA also makes the point that ‘...independent advocacy organisations already possess great expertise in supporting people with disability to make decisions and are well placed to deliver decision support with adequate additional funding (p.4); and ‘Establish an ongoing funding stream for supported decision making’ Recommendation 4 d. (page 15).
- <sup>iv</sup> Disability Advocacy Network Australia (2022) *DANA Submission: Independent Disability Advocacy (submission to the Disability Royal Commission on Violence, Abuse, Neglect and Exploitation of people with Disability*, Draft November 2022. See, also Anne Daly, Greg Barrett and Rhiân Williams (2017) *A Cost Benefit Analysis of Australian independent disability advocacy agencies’* – Report commissioned by Disability Advocacy Network Australia, August 2017
- <sup>v</sup> See, Douglas, J. & Bigby, C. (2020) Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability, *Disability and Rehabilitation*, 42:3, 434-441, DOI: 10.1080/09638288.2018.1498546
- <sup>vi</sup> The State of Victoria (Family Safety Victoria) (2018) *Everybody Matters: Inclusion and Equity Statement* Melbourne: Treasury Place. Available at: <https://www.vic.gov.au/everybody-matters-inclusion-and-equity-statement>
- <sup>vii</sup> The State of Victoria (Family Safety Victoria) (2018) *Everybody Matters: Inclusion and Equity Statement* Melbourne: Treasury Place. Available at: <https://www.vic.gov.au/everybody-matters-inclusion-and-equity-statement>
- <sup>viii</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>ix</sup> DANA (Disability Advocacy Network Australia) (2022) *DANA Submission: Independent Disability Advocacy*, Draft, November
- <sup>x</sup> The State of Victoria (Family Safety Victoria) (2018) *Everybody Matters: Inclusion and Equity Statement* Melbourne: Treasury Place. Available at: <https://www.vic.gov.au/everybody-matters-inclusion-and-equity-statement>
- <sup>xi</sup> DANA (Disability Advocacy Network Australia) (2022) *DANA Submission: Independent Disability Advocacy*, Draft, November.
- <sup>xii</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>xiii</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>xiv</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>xv</sup> DANA (Disability Advocacy Network Australia) (2022) *DANA Submission: Independent Disability Advocacy*, Draft, November
- <sup>xvi</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>xvii</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>xviii</sup> The State of Victoria (Family Safety Victoria) (2018) *Everybody Matters: Inclusion and Equity Statement* Melbourne: Treasury Place. Available at: <https://www.vic.gov.au/everybody-matters-inclusion-and-equity-statement>
- <sup>xix</sup> DANA (Disability Advocacy Network Australia) (2022) *DANA Submission: Independent Disability Advocacy*, Draft, November

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- <sup>xx</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>xxi</sup> The State of Victoria (Family Safety Victoria) (2018) *Everybody Matters: Inclusion and Equity Statement* Melbourne: Treasury Place. Available at: <https://www.vic.gov.au/everybody-matters-inclusion-and-equity-statement>
- <sup>xxii</sup> DANA (Disability Advocacy Network Australia) (2022) *DANA Submission: Independent Disability Advocacy*, Draft, November
- <sup>xxiii</sup> See <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/data>, See prevalence of disability tables.
- <sup>xxiv</sup> A search was undertaken of DRC documents (using the following search terms - 'ABI', 'Acquired', 'People with ABI', 'People with Acquired Brain Injury', 'Brain'. The search was applied to the contents of: Disability Royal Commission Progress Reports; Issues and Research papers; Roundtables and was applied to the titles of nearly 4000 submissions, public hearings (and some transcripts in key areas relating to housing, health and inclusive education. As we present information in this submission, we shall draw on the rather limited references to people living with Acquired Brain Injury in these documents.
- <sup>xxv</sup> In this submission the #<number> format relates to which case study this quotation was taken from
- <sup>xxvi</sup> In this submission Violence (with a capital) is used as a shortened version of violence, abuse, neglect and exploitation'.
- <sup>xxvii</sup> United Brains is a network of self-help and self-advocacy and support groups for people living with ABI in Victoria. See: <https://www.unitedbrains.org.au/>
- <sup>xxviii</sup> See, <http://leadershipplus.com/wp-content/uploads/2022/01/LPlus-ANNUAL-REPORT-2021.pdf>
- <sup>xxix</sup> The survey received responses from 56 individual advocates: 59% (n=33) were from Victoria, 15% (n=8) from New South Wales; 11% (n=6) from Northern Territory 7% (n=4) from South Australia and Western Australia and 2% (n=1) from ACT.
- <sup>xxx</sup> Synapse (2022), *People with hidden disabilities describe adjustments needed to mainstream services*, A co-design session between Synapse and people living with ABI was hosted by the DRC and ., emphasises the hidden nature of their disability. Indeed, 'One group member pointed out that the universal symbol of disability, a person in a wheelchair, 'does not reflect the experiences of every person with disability'. The group talked about how policy can also be blind as a result so down to basic things such as public transport or shopping can be inaccessible and ill-suited to people living with ABI  
<https://comms.external.royalcommission.gov.au/v/89073/1396387/email.html?k=imU0XMcUJJH5gWBb TEH nfDVO2htNwwlfabegzz8s>
- <sup>xxxi</sup> The State of Victoria (Family Safety Victoria) (2018) *Everybody Matters: Inclusion and Equity Statement* Melbourne: Treasury Place. Available at: <https://www.vic.gov.au/everybody-matters-inclusion-and-equity-statement>
- <sup>xxxii</sup> For example, see: Williams, C. (1995) *Invisible Victims: Crime and abuse against persons with learning disabilities*, London: Jessica Kingsley Publications; Gil-Llario, M.D., Morell-Mengual, V., Díaz-Rodríguez, I. and Ballester-Arnal, R., 2019. Prevalence and sequelae of self-reported and other-reported sexual abuse in adults with intellectual disability. *Journal of Intellectual Disability Research*, 63(2), pp.138-148.Olsvik, V.M., 2006. Vulnerable, Exposed and Invisible: A Study of Violence and Abuse against Women with Physical Disabilities. *Scandinavian Journal of Disability Research*, 8(2-3), pp.85–98. DOI: <http://doi.org/10.1080/15017410600731343>; Corbett, A., 2018. *Psychotherapy with male survivors of sexual abuse: The invisible men*. Routledge.; Haag, H., Jones, D., Joseph, T. and Colantonio, A., 2022. Battered and brain injured: traumatic brain injury among women survivors of intimate partner violence—a scoping review. *Trauma, Violence, & Abuse*, 23(4), pp.1270-1287.
- <sup>xxxiii</sup> The State of Victoria (Family Safety Victoria) (2018) *Everybody Matters: Inclusion and Equity Statement* Melbourne: Treasury Place. Available at: <https://www.vic.gov.au/everybody-matters-inclusion-and-equity-statement>
- <sup>xxxiv</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.
- <sup>xxxv</sup> See for example DAV (2022) paragraph 141 and 142 p. 39
- <sup>xxxvi</sup> See, Norman, A., Curro, V., Holloway, M., Percuklievska, N. & Ferrario, H. (2022): Experiences of individuals with acquired brain injury and their families interacting with community services: a systematic scoping review, *Disability and Rehabilitation*, DOI: 10.1080/09638288.2022.2043465. In reviewing 101 papers these authors

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found people living with ABI were challenged by unmet needs and barriers to accessing community services, much like our sample. They also found that knowledge of ABI by professionals was a contributing factor in access to health and social care services.

<sup>xxxvii</sup> The NDIS can fund core, capital or capacity building supports. Under the supports it can deliver<sup>xxxvii</sup> it lists ‘assistance with daily life’ and ‘coordination of supports’ both of which seem relevant to the troubles people living with ABI may have in managing their everyday affairs. So why is this not recognised and funded sufficiently?

<sup>xxxviii</sup> Examples of how domains have been targeted in the DRC work: Group homes - Public Hearings 2 and Issues Paper (Nov, 2019); Employment – Public Hearing 9, 19 and Issues Paper (May 2020); Education – Public hearing 7 and Issues Paper (Dec, 2019); Health – Public Hearings 3, 10 and issues Paper (Dec, 2019); Restrictive practices – Public Hearing 6 and Issues Paper (May 2020); Criminal justice system, Public Hearing 11 and Issues paper (Jan 2020) and research Report (August, 2021; Human rights: Public hearing 18

<sup>xxxix</sup> See Disability Royal Commission (2021) *Disability in Australia: Shadows, struggles and successes*, November. This study found that for people with intellectual disability, ‘safety’ referenced for them environment, or being out in a group but that ‘In contrast, people living with physical, acquired or psychosocial disability tended to discuss safety in terms of needing to keep safe from the actions of other people or from systems. They talked about safety in familiar environments and being at greater risk to the actions of others owing to living with a disability’ (p.47).

<sup>xl</sup> Disability Royal Commission (2020) Hierarchies of power: Disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability. (Author: Shane Clifton).

<sup>xli</sup> Brain Injury Australia and including Monash University, Domestic Violence Victoria, No to Violence incorporating the Men’s Referral Service and the Centre for Excellence in Child and Family Welfare (2018) *The prevalence of acquired brain injury among victims and perpetrators of family violence*, BIA: Melbourne; and, Disability Royal Commission (2021) *Violence at Home Issues Paper*, pp5-6.

<sup>xlii</sup> See case study of Alix, [DRC \(2021\) Police responses to people with disability](#). Authors, L. Dowse, S. Rowe, E. Baldry and M. Baker. September, p.87 in which it is stated that ‘He has an acquired frontal lobe brain injury (ABI) sustained when he was 16 in a car accident. Alix’s ABI causes him to have difficulty concentrating for long periods. He lacks understanding of his impact on others, can be verbally aggressive and has trouble controlling his impulses and emotional reactions to challenging situations’.

<sup>xliii</sup> See, Norman, A., Curro, V., Holloway, M., Percuklievska, N. & Ferrario, H. (2022): Experiences of individuals with acquired brain injury and their families interacting with community services: a systematic scoping review, *Disability and Rehabilitation*, DOI: 10.1080/09638288.2022.2043465. In reviewing 101 papers these authors found people living with ABI were challenged by unmet needs and barriers to accessing community services, much like our sample. They also found that knowledge of ABI by professionals was a contributing factor in access to health and social care services.

<sup>xliv</sup> Interestingly a study on interaction in self-help groups for women ‘brain injury survivors’ (Gelech, Bayly and Desjardins (2017) found such groups to focus on ‘constructing competent selves; tempering the threat of loss and impairment; resisting infantilisation and deligitimisation; and asserting collective gender identity’. Geleclj, J., Bayly, M. and Desjardins, M. (2017). Constructing robust selves after brain injury: positive identity work among members of a female self-help group, *Neuropsychological Rehabilitation*, DOI: 10.1080/09602011.2017.1308872

<sup>xlv</sup> The majority of **Hear My Voice** workshop members had not heard about the Information, Linkages and Capacity Building (ILC) which is funded by the NDIS to support community development. Most participants simply could not see how this could possibly replicate the peer support groups they had once used.

<sup>xlvii</sup> See, Sloan, S., Callaway, L., Winkler, D., McKinley, K. and Ziino, C., 2012. Accommodation outcomes and transitions following community-based intervention for individuals with acquired brain injury. *Brain Impairment*, 13(1), pp.24-43. They found ‘that 77% of their 13 participants with extremely severe brain injuries reported a change in their living situation following injury and 46% required 24-hour supervision or assistance. At 8-years post-injury, over two thirds of the participants were living with parents or family, or within disability shared supported accommodation (SSA) or residential aged care (RAC)’, p.25.

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<sup>xlviii</sup> See Wright, C., Colley, J., Knudsen, K. & Kendall, E. (2019). Exploring the efficacy of housing alternatives for adults with an acquired brain or spinal injury: A systematic review. *Brain Impairment*, 1-29.

doi:10.1017/BrImp.2019.33. They argue, 'Lower levels of community integration/ participation, independence, psychosocial well-being and quality of life for adults...with ABI living in 'structured settings' (i.e., residential care) compared to those living in 'home-like' environments (i.e., private homes) and 'disability-specific' settings (i.e., shared supported accommodation, group homes, foster care homes, cluster units)' (p.2).

<sup>xlix</sup> See for example <https://www.habitatvic.org.au/victorias-housing-crisis>

<sup>l</sup> See, Landau, J. and Hissett, J., 2008. Mild traumatic brain injury: Impact on identity and ambiguous loss in the family. *Families, Systems, & Health*, 26(1), p.69. Citing another study, they report that, change in marital status of 131 subjects who had brain injuries of varying severity. All subjects had been married or living with a partner for at least one year prior to the injury. In follow-up, an average of eight years postinjury, it was found that only 39.69% remained married... Almost half of all subjects, 48.86%, had been divorced or separated', (p.72).

<sup>li</sup> In response to Recommendation 171 of the Victorian Royal Commission into Family Violence, Brain Injury Australia (2018) 'recognise the potential for acquired brain injury to contribute to both perpetration and victimisation in family violence' and note, 'a strong association between brain injury and family violence, and significant gaps in service responses' (p.7). See Australia, Brain Injury, Domestic Violence Victoria, and No to Violence (2018) "*The prevalence of acquired brain injury among victims and perpetrators of family violence.*" Brain Injury Australia. Marickville, NSW.

<sup>lii</sup> Leadership Plus thinks SRSs are not an appropriate place for people living with ABI. They are privately run facilities with a minimum staff ratio of 1:15. Most SRSs in which people with ABI are accommodated are what is known as 'pension level', meaning the cost is 80-90% of the pension, covering minimal care, utility costs, laundry and meals, leaving approximately \$20 - \$30 per fortnight to cover personal costs such as toiletries, recreation, phone, travel and other personal needs. It is also worth noting that an SRS plays no part in building living skills. In fact, Leadership Plus would argue that SRS accommodation de-skills individuals.

<sup>liii</sup> See, Schmitt, T., Thornton, A.E., Rataer, I., Barr, A.M. etc al (2017) Traumatic Brain Injury in a community Based Cohort of homeless and Vulnerably Housed Individuals, *Journal of Neurotrauma*, 34, 23 <https://doi.org/10.1089/neu.2017.5076>. They show that, 'Previous TBI (Traumatic Brain Injury) is associated with poorer mental and physical health in homeless and vulnerably housed individuals and interacts with mood disorders to exacerbate poor mental health' (p.00)

<sup>liv</sup> This has been exacerbated with rental freeze during COVID no longer applying and with rents once again subject to market forces.

<sup>lv</sup> See DAV (2022) which states that '0. Looking at data about why people with disability are not able to escape violence and abuse, we found that the lack of resources to do so is the biggest issue' (DAV, 2022, paragraph 150, p. 41.

<sup>lvi</sup> See Houston, V., Foster, M., Borg, D.N., Nolan, M. and Seymour-Jones, A. (2020) From Hospital to Home with NDIS funded support; Examining participant pathway timeframes against discharge expectations, *Australian Social Work*, 73, pp 175-190; Laurie, K., Foster, M., & Gustafsson, L. (2022). Personal experiences of appropriate access to post-acute care services in acquired brain injury: A scoping review. *Brain Impairment*, 1-26. doi:10.1017/BrImp.2021.33

<sup>lvii</sup> It has been suggested 'transitional units' and 're-entry programs' may be useful approaches to this crucial transition period. See, Tuelle, J.L., Von Wid, K. and Montreuil, M. (2010) Social reintegration of Traumatic brain injured: The French Experience, *Asian Journal of Neurosurgery*, 5,1, pp24-31.

<sup>lviii</sup> See, Dwyer, A., Heary, C., Ward, M. and MacNeela, P. (2019) Adding insult to brain injury: young adults' experiences of residing in nursing homes following acquired brain injury, *Disability and Rehabilitation*, 41:1, 33-43, DOI: [10.1080/09638288.2017.1370732](https://doi.org/10.1080/09638288.2017.1370732). Quote from p. 34.

<sup>lix</sup> DANA (2022) op cit say 'There is increasing recognition of the multiplier effects of intersectional disadvantage for people who have disability along with health and/or other issues that influence their well-being - for example, welfare, poverty, housing and justice related issues' (p.7). Leadership Plus agrees with this statement.

<sup>lx</sup> In the Brisbane Public Hearing transcript (Monday 7<sup>th</sup> December 2020) the following useful case study of Jamie exemplifies the struggles with employment, 'Jamie is 58 years old. He has a vision impairment and an Acquired Brain Injury. He has 10 several tertiary qualifications, including a Master of Human Services and a Master of Social Work. He has spent over 20 years volunteering to develop his skills and experience. His



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opportunity for paid work has been limited and generally through ADEs. During some recent employment with an ADE, he was paid an hourly rate of \$3.51. He says this is not nearly enough to cover the necessities of life... A lifetime of unemployment and underemployment has ruined my life and left 20 me welfare dependent' (p.16). DRC Public Hearing, 24<sup>th</sup> March 2021 – 'Pamela "Ella" Darling, a young woman who lives with an Acquired Brain Injury, spoke about her experiences in a number of different jobs... hours without days off; being poorly paid; paid less than someone doing the same type of work; not being given the opportunity to complete new and different types of work which she was qualified to do; being subject to inappropriate and disrespectful comments; lack of management assistance for complaints and questions; and 5 exclusion and verbal bullying' (p-463)

<sup>lxi</sup> DRC Public Hearing, 24<sup>th</sup> March 2021 provides the following example, 'Jamie gave evidence that some of the impacts of his Acquired Brain Injury include -- 40 - he said this: "difficulty focusing on a task and understanding non-verbal communications in order to understand social situations." Jamie explained that this means it can take longer for potential employers to really get to know him' (p-467).

<sup>lxii</sup> Grauwmeijer, E., Heijenbrok-Kal, M., Haitsma, I & Ribbers, G (2017) Employment Outcome ten years after moderate to severe traumatic brain injury: a Prospective cohort Study, *Journal of Neurotrauma*, 34, 17, pp. 2575-2581. These authors followed 109 people living with ABI over ten years and found 12% employed 3 months after injury, 57% two years after follow-up, but 43% ten years after injury. Our interest in this section is with the substantial number who do not find suitable employment.

<sup>lxiii</sup> In the Brisbane Public Hearing transcript (Monday 7<sup>th</sup> December 2020) the following useful case study of Jamie exemplifies the struggles with employment, 'Jamie is 58 years old. He has a vision impairment and an Acquired Brain Injury. He has 10 several tertiary qualifications, including a Master of Human Services and a Master of Social Work. He has spent over 20 years volunteering to develop his skills and experience. His opportunity for paid work have been limited and generally through ADEs. During some recent employment with an ADE, he was paid an hourly rate of \$3.51. He says this is not nearly enough to cover the necessities of life... A lifetime of unemployment and underemployment has ruined my life and left 20 me welfare dependent' (p.16) ; DRC Public Hearing, 24<sup>th</sup> March 2021 – 'Pamela "Ella" Darling, a young woman who lives with an Acquired Brain Injury, spoke about her experiences in a number of different jobs... hours without days off; being poorly paid; paid less than someone doing the same type of work; not being given the opportunity to complete new and different types of work which she was qualified to do; being subject to inappropriate and disrespectful comments; lack of management assistance for complaints and questions; and 5 exclusion and verbal bullying' (p-463)

<sup>lxiv</sup> See, Karthik, M., Cater, B. and Ahshay, H. (2017) Cognition and return to work after mild/moderate traumatic brain injury: A systematic review, *Work*, 58, 1, pp51-62. They found cognition plays a significant role in predicting and facilitating return to work. Like many of our points it is the incapacity of current *systems* to adapt to diversity and differences that are a problem for people living with an acquired brain injury: Donker-Cools, B., Daams, J., Fings-Dresen, M. (2016) Effective return-to-work interventions after acquired brain injury: a systematic review, *Brain Injury*, 30, 3, 113-131. See also, Liaset, I.F. & Loras, H (2016) Perceived factors in return to work after acquired brain injury; A qualitative meta-analysis, *Scandinavian Journal of Occupational Therapy*, 23, 6, pp446-457. <https://doi.org/10.3109/11038128.2016.1152294>

<sup>lxv</sup> Grigorovich, A., Stergiou-Kita, M., Damianakis, T., Le Dorze, G., Lemsky, C. & Hebert, D. (2017): Persons with brain injury and employment supports: Long-term employment outcomes and use of community-based services, *Brain Injury*, DOI: 10.1080/02699052.2017.1280855. See also Bould, E., & Callaway, L. (2021). A co-design approach to examine and develop pathways to open employment for people with acquired brain injury. *Brain Impairment*, 22(1), 50-66. doi:10.1017/BrImp.2020.9

<sup>lxvi</sup> See O'Brien, M.T. (2022). Brain injury and prison: over-representation, prevention and reform, *Australian Journal of Human Rights*, DOI: [10.1080/1323238X.2022.2093462](https://doi.org/10.1080/1323238X.2022.2093462). This is further supported 'Advocates identified that people with cognitive impairment comprise the largest group of people with disability who come into contact with the police. This reflects the key findings from the literature review' in DRC (2021) *Police responses to people with disability*. Authors, L. Dowse, S. Rowe, E. Baldry and M. Baker. September, p.74

<sup>lxvii</sup> Disability Royal Commission (2021) *Agents of our own destiny: Activism and the road to the Disability Royal Commission*, November. This document states that 'a Victorian Department of Justice report that 42 per cent of male prisoners and 33 per cent of female prisoners had an acquired brain injury' (p.15) which emphasises why people with ABI are so fearful of ending up in this system.

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<sup>lxviii</sup> See Disability Royal Commission (2021) *Police responses to people with disability*. Authors, L. Dowse, S. Rowe, E. Baldry and M. Baker. September. The case of Andrea (p. 77),

<sup>lxix</sup> Lansdell, G. et al., (2022) op cit.

<sup>lxx</sup> The term 'cumulative adversity' can be found in Lansdell, G., Saunders, B.J., and Eiriksson, A. (2022) *Young people with acquired brain injury: preventing entrenchment in the criminal justice system*. Canberra: Australian Institute of Criminology. The authors usefully demonstrate how for young people such 'cumulative adversity' affects their engagement with the criminal justice system. It is our contention that this useful concept may be applied to the lives of people living with ABI more broadly.

<sup>lxxi</sup> Disability Royal Commission (2021) *Police responses to people with disability*. Authors, L. Dowse, S. Rowe, E. Baldry and M. Baker. September. The case of Andrea (p. 77 of the same report) shows how a person with ABI amongst other disabilities found it hard to achieve justice based on discriminatory behaviour by the police and others.

<sup>lxxii</sup> Disability Royal Commission (2022) Overview of responses to the criminal justice system Issues Paper. On page 5 the Australian Lawyers Association states that '...people with intellectual disability and acquired brain injury may face negative assumptions in court, such as negative assumptions about their credibility or reliability as a witness' and, linked to the invisibility of their ABI 'to plead guilty through their legal aid representation. That is especially so if the lawyer is unable to identify the client's disability or impairment due to inadequate training or time pressures'.

<sup>lxxiii</sup> E.g. See: O'Brien, M.T. (2022) Brain injury and prison: over-representation, prevention and reform. *Australian Journal of Human Rights*, pp.1-20; Eiriksson, A., Saunders, B. and Lansdell, G.T., 2021. Neurodisability and the revolving prison door: an international problem viewed through an Australian lens. In *Neurodisability and the Criminal Justice System* (pp. 195-212). Edward Elgar Publishing.

<sup>lxxiv</sup> DRC Fourth Progress Report (2021), August, presents the case study of Tarni (p.48/9) which usefully exemplifies how resistance by State Trustees and Guardian, despite the person's will and preference led to a protracted period in which travel home to country for one woman became a very lengthy battle despite her having the funds to make that visit. The result was that due to her ABI and depression she became more vulnerable over time.

<sup>lxxv</sup> DRC (2022) Roundtable – Supported decision-making and guardianship: Summary Report. October 2022.

<sup>lxxvi</sup> Disability Advocacy Network Australia (2022) *DANA Submission: Independent Disability Advocacy (submission to the Disability Royal Commission on Violence, Abuse, Neglect and Exploitation of people with Disability)*, Draft November 2022. See, also Anne Daly, Greg Barrett and Rhiân Williams (2017) *A Cost Benefit Analysis of Australian independent disability advocacy agencies' – Report commissioned by Disability Advocacy Network Australia*, August 2017

<sup>lxxvii</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.

<sup>lxxviii</sup> See, Douglas, J. & Bigby, C. (2020) Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability, *Disability and Rehabilitation*, 42:3, 434-441, DOI: [10.1080/09638288.2018.1498546](https://doi.org/10.1080/09638288.2018.1498546)

<sup>lxxix</sup> Disability Advocacy Victoria (DAV) (2022) *Submission: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, DAV, October.

<sup>lxxx</sup> DANA (Disability Advocacy Network Australia) (2022) *DANA Submission: Independent Disability Advocacy*, Draft, November

<sup>lxxxi</sup> See also, Elizabeth Tilley, Iva Strnadová, Joanne Danker, Jan Walmsley, Julie Loblinzk (2020) "The impact of self- advocacy organizations on the subjective well-being of people with intellectual disabilities: A systematic review of the literature." *Journal of Applied Research in Intellectual Disabilities*, 33(6): 1151-1165.

<sup>lviii</sup> Disability Royal Commission (2020) *Interim Report*. Commonwealth of Australia: Barton ACT, p.4.

lix Leadership Plus also recognises that where systems do not recognise the wishes and needs of people living with ABI then these needs are effectively unseen. We make this point throughout this submission in relation to assessment, understanding key dimensions of living with ABI and in relation to appropriate services and access to those services.