2022

Submission to Disability Royal Commission on Violence, Abuse, Neglect and Exploitation of people with disabilities.

Hear My Voice

Steps to prevent violence, abuse, neglect, and exploitation for people living with acquired brain injury

Leadership Plus

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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 injuries.

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.

Section 1 - Understanding the views of people with Acquired Brain Injury

A. Introduction

With a Human Rights Framework and commitment to co-design and lived experience at the core of our work, Leadership Plus conducted research and consultations around the specific risks and advocacy needs of people with Acquired Brain Injury, as part of developing submission to the Disability Royal Commission. Highlighting the voices, experiences, and issues relevant to people with Acquired Brain Injury, we hope to assist the Royal Commission to better understand the needs of people with ABI.

This report has been developed as a result of four workshops with people with Acquired Brain Injury (ABI), organised and facilitated by Leadership Plus and drives our recommendations by highlighting how codesign establishes strong grounds and mechanisms for change. It is submitted as an accompanying document to our submission to DRC and should be read alongside positions outlined therein.

Leadership Plus reached out to people with lived experience of ABI through a call for Expressions of interest, mainly through our networks. The participants identified as being part of a support or self-advocacy group and were asked to consider those they represented when contributing to the workshops.

This document tells the DRC what the ten participants with ABI told us during the workshops. The document has then been shared with the group to review, suggest changes, and sign off on.

The people who participated in the workshop were: Anonymous person; Lisa; Eva; Peta; Sonia; Adrian; Neil King; Larissa McFarlane; Eva Sifs; Neil Cameron

(The participants chose how to identify themselves and reference their contribution).

B. Understanding Views

First the DRC should know that people with ABI were simply not sure what difference they could make – or the DRC could make[1].

We speak out

But we are told “we can’t do this or change this..”

We are disenfranchised …we are erased.

- *Even if they [DRC] hear what we have to say, what will we or what will it achieve anyway?*
- *Everybody in our group feels that they can scream as loud as they want, they can say what they want, they can do all the protesting. But, if nothing happens, what's the point?*
- *I don't know how effective it will be, because we're just preaching to the converted and we're preaching to the people who continue to disparage our voices.*
- *They [the government] consider us a weak lobby group because a lot of us are voiceless. I don’t think they can imagine [what it is like for us].*
- *I think the word is [that we’re] disenfranchised.*

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[1] *A couple years ago, when it first came out and I thought, well, I can't really contribute even though I have an ABI and a disability. I don't see how I can contribute to the Royal Commission.*

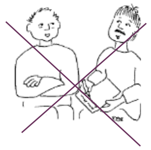
What is the ‘Good Life’ for people with ABI?

People with ABI questioned what the ‘good life’ is for them and why the facilitators had asked them about it.

The good life?

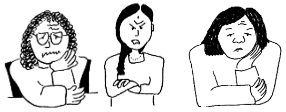
- *I don’t actually know what that [the good life] means anymore. I don’t think any of us do. There are too many barriers to even think about an ideal life, so it just becomes about managing the day-to-day.*
- *It is confusing because there aren’t the services available and many community groups and services for services for people with ABI were defunded when the NDIS came along.*
- *I am disillusioned [because] everything is so inaccessible.*
- *I’m not allowed to improve myself. I’m not able to actually reach for the good life.*
- *[I feel] bloody frustration and anger and then just get on with things.*

The “good life”?



No services or supports

Pointless having plans



Fed up, angry and disillusioned

People with ABI seem to have stopped reaching for the good life, why?

Here are some things the participants said about the ‘good life’.

- *In regards to this issue of the good life, the best life or better life, whatever, recognizing that the barrier that prevents us from having a good life is more to do with the discrimination and ableism[2] than it is to do with our brain injuries.*

- *It's a matter of survival. And that just made me think of something, I feel like we're just expected to survive. We're not expected to live. [Facilitator: You can't flourish?] Exactly right. It's like we’re not allowed to because we made the mistake of acquiring a disability.*

- *We find goodness, where the key to survival is to find goodness wherever you turn. So perhaps these lives are not our ideal lives, but that separates them from being good. I mean I have found a positive life.*

- *We want the good life. I don't think that's ever gonna be achievable for any of us. But we want to have a better life.*

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[2] *‘I feel put into a very difficult situation because I feel like I'm being forced to live an able-bodied life… And I wanna assistance to live the best ABI life that I can’.*

So what is achievable and what barriers are there to having a better life?

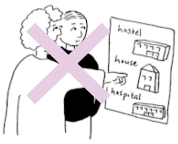
- Having meaning in life… we need opportunities to be able to find new meaning after we lose so much. And I guess through love and belonging and all that stuff, how that happens is when we feel like we have a place on the planet... and a reason to be here.

Some felt acquiring their disability had been a positive experience

- *Really, the brain injury has brought me so much. It has brought me so much awareness. It has brought me so much compassion. It has brought me so many opportunities. It has brought me so many chances to better myself in a way that I don't believe I would have taken had I not had the injury. It's been hard work.*

People with ABI need to find meaning to life, a place in the world and a reason to be here. But there are a lot of things that stop this from happening that are all related to each other.

There is a downward spiral of rejection and exclusion is more likely for people with ABI

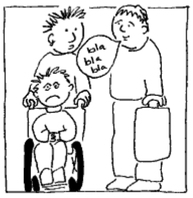


Exclusion from good & safe housing

Rejection in the community

Rejection from paid work and job applications

No support for personal development and training



Friends & family can reject, exclude or worse

Insufficient financial security. Centrelink payment issues

This is what I want

Inaccessible and insufficient services and supports

Result - The system has erased me. I don't know how to complain, I can't change anything, I can't even think about the good life - what is it? It does not apply to me. I cannot afford to have hope. I am poor, more vunerable to exploitation, abuse, neglect and violence.

Section 2 - Understanding the experiences of people with ABI

A. How to read Section 2 of this submission.

The diagrams in this section state a key need (in purple) for people with ABI. Following the arrows between boxes, the experiences of people with ABI are provided, along with the barriers they face.

The diagrams are followed by a question asking what services and other things can address the barriers and include comments and statements from the participants about what needs to change.

Some detailed quotes, points and stories are shared in the footnotes as well.

Note: The group recognises that they do not and cannot cover everything and this document is a result of discussions during workshops only.

KEY NEED
To be able to exist means having money, being financially secure and having meaningful career and volunteering options.
It means a positive identity about who I am and what I do and being free from financial abuse

After acquiring my disability:

- My expected career progression could stop
- I may not be able to enter the workforce (for the first time)
- Due to discrimination, I may not be successful with job applications
- Due to health issues I may not work as much as before
- I may only ever get casual work and this leaves me poor and stressed
- I may have to do work I do not want to do

AND/OR

- I may have to claim Centrelink payments
- Because of my injury being hidden I find it hard to qualify for Disability Support Pension (DSP).
- It is too risky to come off the Disability Support Pension to pursue desirable work options because often jobs do not work out and getting back on the pension is a nightmare
- I spend my life dealing with the systems. It's a job in itself
- Disability employment services are useless

Positive things:

- When I have a positive identity, I can contribute
- My personal development continues all the time. I would not have done that if I had not got my ABI which requires me to work on myself too
- I know I have things to offer if others would see that
- I gain a new sense of meaning to my life

Personal development

New Meaning

Diversity

Barriers. There can be:

- A crisis in the person's sense of identity and self esteem
- Exhaustion for the person having to prove him/herself all the time
- A change in the life the person has come to expect, given their income
- Huge difficulties getting a job
- Trouble finding a way out of the poverty and Centrelink payment traps
- People are terrified of being booted off the DSP
- Lack of funding means the person cannot afford to be the person they want to be
- Limitations to afford the leisure, holidays and trappings of the good life.
- Lack of control over my own money because of Guardians/State Trustees/Family

I do not know who I

am anymore:

I'm exhausted. Cannot get a job

No. You cannot have DSP.

I just cannot afford this

I'm trapped by the system

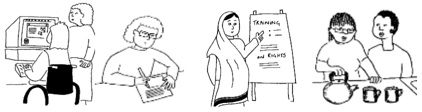
So, what services, supports and other things can make sure you achieve these outcomes? Why does this not happen?

- *A positive approach is needed and recognition of abilities – Having an ABI doesn't necessarily affect a person's professional capabilities.*[3]

- *There are so many ways we cannot make a living because of the rules. We are expected to volunteer or work for free and this is exploitation; we cannot earn over a certain amount on the Disability Support Pension*[4]*. This is systemic abuse and exploitation. We need to change the rules to protect, defend and ensure our rights*[5]*.*

Job seeker? It's more like punishment for having an ABI.

You know the Centrelink and employment rules



I still have skills

Our rules are more important than your wellbeing

Just obey. It doesn't matter you're poor or might lose your rental. Just comply

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[3] *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 a person's prior skills. I was a manager. I managed, I hired people, I fired people and yet after the injury, I was only good for factory floor.*

[4] Some examples of the perverse rules which impoverish people are the following: *My wife actually wants to go back to full time work. But basically, we lose benefits that we actually need, because I can't work. And so she's forced to work 25 hours a week*; *I'm also sick of disability jobs being voluntary as if our lives are cheap or they want able bodies working in those disability jobs*; *My husband has MS. If he has to stop work we will lose our rental.*

[5] *I think once we once we come out of the workforce, we're not considered as a worthwhile human being and that's why Australian governments really need to take action about a Bill of Rights.*

I can't go off DSP by taking this job

- *Having more control over one's own money means choice and control over one's own life[6]. Guardians, State Trustees and others can make it difficult and ignore the will and preference of the person. This needs to be addressed.*

- *Better employment services are needed. Job Seeker is exhausting and for many leads nowhere in terms of a meaningful career. People are scared of what will happen if they come off the Disability Support Pension. Rules need to change.*

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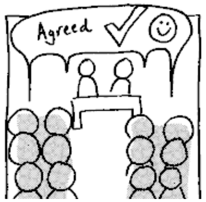
[6] *Wrestling control of my own money from Guardians and State Trustees is a real problem.* The transfer of power back to the person is often confrontational. Power is often held by the Guardians or State Trustees who err on the side of wanting *no risk*. They employ many tricks such as paying for non-independent neuropsych and other assessments. The use of lawyers by the TAC who purchase their assessments to challenge the person's brain injury are another example of where there is no independence. The powers held by such organisations can be used against people with ABI and few have the knowledge, means or advocacy to contest this power. A participant shared his experience of employing lawyers on his own and the group acknowledged that not everyone with an ABI has the know-how, stamina, understanding or motivation to adopt these approaches. Indeed, sometimes the whole method of making a decision is taken out of the person's hands entirely, for example when such decisions take place in courts or tribunals. So, most people with ABI 'have no say'. The person's 'will and preference' should play a stronger role in deciding an outcome and new, less confrontative, means of supporting and testing the transfer of power over funding need to be adopted. These systems abuse a person's financial security, their choice, and the pursuit of lives of their own choosing. Examples shared by the group included State Trustees denying a person access to their own property for years affecting their life trajectory irremediably and Guardians using their 'own' experts (i.e., ones they pay) to back up their position. Additionally, there may be lack of control at home. One person said: *people with disability who are in a relationship, if their partner is their main source of income, the person with a disability could be trapped in that relationship. This is horrible if the relationship is abusive or, in my case, I feel less of a person because I can't financially support myself.*

- *People should not be expected to work for no or low pay. That is exploitation.*[7]

- *The rules on the DSP need to change. Our eligibility for the DSP should not be annulled after two years. Our disability does not disappear when our employment ends.*[8]

I can do better than this

New Centrelink DSP rules



This person [neuropsych] is being paid to tell Guardians I am not able to manage my own money. That's not right

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[7] *Nothing has changed in my job except we are expected to do more and more with the same funding, groups in the community sector don't have the recurrent funding, and workload has increased; A lot of people stay on Centrelink benefits, they are put into a difficult position, if you have a partner and, in a relationship, your finances are completely screwed over. If your partner has income… But then on the other side, if you were living with someone, if you are in, say, an abusive relationship and you are stuck there because that could be your only source of funding.*

[8] *It wasn't so hard to get on DSP. But when I came off it and wanted to reapply it literally took me years to even apply. Centrelink didn't wanna interview me I applied three times. I had a support worker come with me to the Centrelink office and that was the only way I got on to the pension again.*

KEY NEED

A safe home of my choice is important to make me feel secure and free from abuse

After acquiring a disability.

I may need a new home because:

- I have not got enough money for my old one
- My family cannot or do not want me in the home we shared prior to injury
- I need significant supports in the home and have to move
- Without the right support I may end up homeless. This also applies if I have been in jail

Barriers. There can be**:**

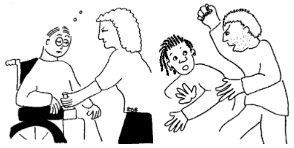
- A break in life course and expectations around housing
- Some end up in a nursing home they have not chosen
- Some never get chosen for rentals because of their ABI
- More vulnerability to violence by others, in a home that is not their own
- Inability to find housemates that are accepting of ABI/disabilities

Your housing plans need to change

It not the staff home. It's mine.

Rejection of my application for home rental.

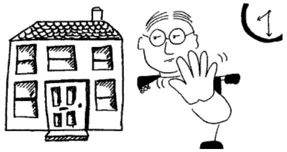
More chance of being bullied or worse.



What services, supports and other things can make sure you achieve this outcome? Why does this not happen?

- *Discrimination is felt in relation to housing[9]. Discrimination against people with disability can take place in the private rental market and this must be changed.[10]*

- *The effects of precarious housing can lead to abuse.*



NO, not for you.

Advocates can protect your rights

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[9] *When I acquired my brain injury I was told public housing was not available to people with ABI…. if I'd registered back then I probably would be in public housing, but no.*

[10] A participant shared their experience when they could not get a rental and their partner without a disability had to organise the rental which they did in a week. Another person had to show a letter saying they would not need any adaptations to the home. Others could not do the gardening because of their disability and got into trouble with the landlord. Many feel fearful of being ‘kicked out of their own home’. 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. Centrelink is not considered ‘real’ income and people are not seen as deserving.

I can talk with other self-advocates about my rights

If I have no choice of where I live, I am more likely to suffer violence and abuse.

Go back to jail.

Homeless and vulnerable

- *Abuse can also happen in family homes. One person shared that they had to take out an intervention order against a housemate and another found himself being abused by a housemate.*[11]

- *Need for independent advocates - Not everyone knows about advocates and about speaking up. Many therefore live with abuse as a result or do not get their housing rights.*

- *The contribution of self-advocacy - Self-advocacy plays a vital role in people being informed about their rights.*

- *Protections for those with ABI in the criminal justice system are really needed– without housing and support when they come out of jail, many end up in dangerous situations and many end up back in jail.*

- *Need for more public housing - Homelessness is not acceptable for people with ABI - Many people end up homeless and this makes them very vulnerable to abuse and neglect. Housing should be close to public transport.*[12]

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[11] *But I feel very abused [in my family home]. And since I've had my ABI, I don't know any different apart from being abused.*

[12] One person said in relation to transport; *a real positive to my life was the introduction of the PT access card for disabled people. Now I experience way less issues with inspectors and the law. It is life changing. Should be across Australia*.

Being accepted by others is important to everyone

After acquiring my disability:

- I found I was not accepted in the community and by people in the same way
- I found myself developing new ways to be heard and accepted – some were good and some not so good
- I joined new groups and went to places where I was accepted
- I had to change my identity – it is a struggle while it's taking place

Positive things:

- I found a new community
- I learned new strategies for being accepted
- I heard about a card [an ID card that states the person's disability] on my disability which was developed by an ABI group. It would be helpful when interacting with others
- I found my strength as a woman
- I celebrate every achievement and goal
- Maintaining my strong identity and self esteem

New friends

Inner strength

New strategies

Barriers: There can be:

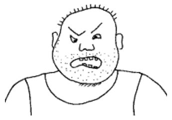
- Challenges to a person's self-identity and esteem
- Feeling that the person has no power and control and that their voice is not heard
- Challenges where some of the strategies for being accepted did not work (e.g., nodding my head when I really did not understand)
- Danger and abuse with some strategies used for being accepted.
- A complete lack of understanding of my "hidden disability" by the public
- Sometimes I vent my frustrations openly in behaviours some other people find challenging

Self-esteem/ identity issues. Silenced

Public do not understand

Sexual abuse

Got openly frustrated



What services, supports and other things can make sure you achieve acceptance? Why does this not happen?


Diversity is a strength

- *Others need to be positive about each person[13]. Too many family members and services focus on the negatives and what people cannot do[14]. They do not recognise the contribution people with ABI can make. Inclusion and accepting diversity mean we are all capable of doing and contributing something.*


Resources about people with ABI by people with ABI

- *The need for resources about ABI: There is few resources for families, the public and services about people with ABI[15]. The role of people with ABI in raising awareness is not taken up and this is a waste of skills.[16]*


People are less likely to protest if their lives are good!!

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[13] *Society generally needs to consider us as being human. I think that's the lacking bit*. The group agreed that, *you either get made invisible, or you isolate so you are invisible and the minute that you're separated out and invisible, you're not seen or heard. Then you feel like you can't come back in*.

[14] *A lot of people in the community think that acquired brain injury is the fault of the person who has the acquired brain injury (though not people after a stroke, MS or Parkinson's) – 'if I had my time again, I would say I had a stroke because I think you would open way more doors for me*; One person was ignored by other parents at her child's school. She went to see the headmistress who took her to talk to the child's class and they understood and then people started talking to her.

[15] One person mentioned the Hitchhikers Guide to ABI, https://www.changedlivesnewjourneys.com/learning-about-brain-injury/. This was seen as important by the NDIS CEO David Bowen, but when a new CEO came in the effort to adopt it and distribute it more widely was lost.

[16] **Bear in Mind** which became **Brain Injury Matters**, used to train police officers in their traineeship about how to respond to the public and to people they did not know had ABI when they first encountered them. It is possible for self-advocacy groups to teach this in the schools and community groups.

Am I not equal to you…and you…and you…and YOU?

The need for advocacy to prevent discrimination and abuse

- *Services and supports to achieve the person's aims*
    - *We need support with personal development, living skills, and practical support to help us reach the life outcomes each of us chooses.*
    - *Some community services have just stopped.*[17]
    - *The NDIS simply does not achieve this for people with ABI and we have so much trouble getting access to it. Even then it does not provide enough assistance in terms of providing a good enough standard of living.*
    - *We need services defined by people with disability instead of services invented by "able-bods" who think they know what they're doing.*
    - *We need better services.*

- *We need individual advocacy to ensure our rights are protected and others don't discriminate against us. The need for self-advocacy and lack of funding was highlighted several times by the participants and is reflected throughout this document.*

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[17] *It is about community and about belonging to the community and how that has disappeared. I was thinking about how I have been part of a disability space community art group. It's been a place where you go and be with community and it has been so important for me. Learning about myself, having people around me, and also my art practice, which is like so much of my identity and what gives me meaning and that service is now closed down with no warning. 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 we learned through community, so it's shut down through the funding structure. All the drop in or the community disability spaces that existed, so many of them have disappeared and quite violently disappeared by just kicking people out. If there are replacements, I don't know how to find them. You've still got to apply. You've still gotta go through all the ableist crap and then being actually refused service because you're too complicated.*

- *We need self-advocacy[18] to build trusted and respected relationships and to discuss our rights and build our skills to stick up for our rights. People need self-advocacy from the youngest age they have ABI or disability.*

- *See who we are and not our ABI[19] – People also mentioned the importance of Intersectionality. People with ABI can be discriminated against because people define them by their ABI – as if they don't have sexuality, culture, gender, or other identities.*

- *See my frustration. Don't stamp out my legitimate behaviours of protest. If people can make their own choices and are supported and their rights are protected then they will not show frustration and protest about their situation and circumstances.*

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[18] The funding for self-advocacy is not sufficient; *I think, our groups have just unfortunately been squashed out.*

[19] Some quotes by participants highlighting the frustrations of working towards finding acceptance were: *the majority of people with ABI are worse off than us and they don't have the capacity to speak for themselves or act for themselves or even what's going on in their lives*; *The wide disability community is so important to be able to find that confidence and that energy and that know-how to be able to do that fight for your own human rights because, we learn from each other and we gain confidence from each other. And without that, it's almost impossible if you're alone, which so many people with ABI are*.

It is important to be organised and have a plan and make sure the plan is turned into action.

After acquiring brain injury people can:

- Experience a lack of memory of things that have happened, or things planned
- May second-guess themselves all the time and do not speak up
- May not keep calendars and diaries well and miss things
- May not keep up with things like forms to be filled and applications to be made
- Find it hard to keep up with all the documents they have to complete and do not really understand what they are all for
- Can't see their own progress over time
- Can go over the same points many times over with others

Barriers. There can be**:**

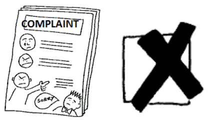
- A lot of disorganisation, with the person unable to keep up with life and its demands
- No movement in pursuing life plans
- A lack of challenging or complaining about the services and supports they should get
- Penalised for not completing paperwork
- Difficulty getting access to services (e.g., NDIS or Centrelink)
- Always having to justify oneself to get services
- Difficulties remembering or sometimes knowing what decisions have been taken

Disorganised

What's this? What Plan?

Penalised for not completing documents

Do not complain or speak up



Many professionals say no to service access. They don't believe you and you have to justify yourself. And they can take one part of an assessment even though there is lots more in the assessment so they can say "no, you cannot access services". This happens a lot in the NDIS access process and then in the one-year planning cycle to actually get on (NDIS)

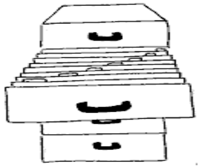
What services, supports and other things can make sure you achieve these things? Why does this not happen?

- *Services in many cases are inadequate. People living with an ABI need much better personalised assistance with navigating their affairs, including physical and financial.*[20]

- *Service systems must not be too bureaucratic - Who on earth understands the NDIS? Who understands the service system? Who understands all the forms and what they are for? Confused? So is everyone else, not just people with ABI*[21]*. It's not just about disability services – private landlords, shops – everything now involves forms and computers. It is complicated.*[22]

Much better personalised assistance needed to navigate life

I'm just not getting enough from services and supports



What can it all mean?

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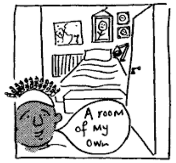
[20] *If their disability is deemed "not substantial enough" by NDIS, they can't get those supports*.

[21] One person said, *Understanding the systems - dealing with Centrelink is bad enough... NDIS would be very difficult, and you need to understand how the system works, a lot of people would find that difficult. Having someone there to explain things to you or having the information that you can understand and just understanding what choice and control is for you*.

[22] *Sorry I can't use a smartphone because of my disability, so there's a thing that you can get on smartphone where you can apply for rentals a lot quicker. But I have to do it by paper*; *Because technology isn't set up for people with disability, it won't, and it doesn't help them. And then they get even more disenfranchised*.

- *Services must be adequate and appropriate.*[23]
- *Services need to change fast and at the moment they cannot respond to changes in our lives.*[24]
  - *Not only do systems take forever, but they are also complex and the process is difficult to understand*
  - *Often you have to fight for your rights*



My life needs to change. But services don't respond quickly enough!

I am now poor and isolated and cannot find a way out

I am now worried and scared and more vulnerable

I'm angry at the level of services and supports

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[23] *But look, I say that sometimes I just have bloody frustration and anger and then I just get on with things. But, you know, when you hear it from somebody else, you realize you're not alone*; *One of my fears for many years has been the fear of incarceration because I felt like my behaviours could be really problematic with police and with professionals*; *When I had my child I was so terrified it'd be taken off me*; *My attempts to try to clear my name twice ended up in me getting a good behaviour bond twice, which is a really scary thing*; One person trying to access the NDIS pointed; *An occupational therapist to write a report to the NDIS, which is gonna cost over $2000, which I couldn't afford to get on the NDIS*; *No we are not eligible for NDIS according to the NDIS… You are all eligible for NDIS, but you haven't jumped all the ridiculous hoops yet… It's like the NDIS has worked to seclude us*; *All this talk about NDIS is great, but how about if you're not eligible for it.*

[24] There was an agreement to this statement by the facilitator; *it takes forever, like you can go through the Appeals tribunal, but it can take two years before you get an outcome and the NDIS will come with lawyers to that appeal. And lots of people don't have access to advocacy or funds for a lawyer to take the NDIS on. It's not fair. There's a complete power imbalance there*.

Love, belonging, intimacy (physical and emotional), family, esteem and friendships are important to me. All these are based on 'being accepted as a person' (see above)

Positives:

- I now know who my real friends are.

Real friends

Barriers. There can be:

- Loss of some friends
- Belonging in family or friendship groups can be an issue
- Isolation
- More chance of bullying at home and elsewhere
- Families infantilise the person
- Issues around culturally and linguistically diverse (CALD) communities and shame

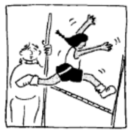
I'm not your friend anymore.

Who can I talk with?

Being bullied

What services, supports and other things can make sure you achieve these outcomes? Why does this not happen?

This is what I want and this is what I can achieve.



I can achieve this. This is me.

- *See our potential - There is such a negative view of people with ABI*[25]*. We need others to see what we can achieve and what we can contribute.*

- *Without respect and acceptance it is hard to build our identity and place in the world*[26]*.*

- *Inclusion is vital - If we are not accepted and we are discriminated against, we have no chance of being included and making the contributions we can make.*[27]

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[25] *There's even a negative view by other people with disability who were born with their disability*.
HIERARCHY OF DISABILITY (Participants wanted this term to be highlighted).

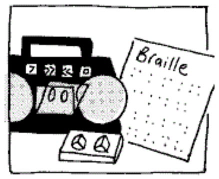
[26] *Ableism is the problem*; *So you're not good enough to be part of the able community. You're not good enough to be part of the disability community. So where do you sit?*

[27] *I feel scared to tell anyone because of what might happen and all that leads to… So 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… And it's very real and it's really scary*; *Basically the people that are around me are just so not worth it, so I chose to and it I've chosen to isolate myself*; *Family and friendship support is so vital but not experienced by all people with ABI and, indeed relationships can be abusive. And if it wasn't for my wife, I don't know where I'd be today*; *It is not like that for everyone. Not everyone has the support of family or others*; *If I say I have an ABI, 'Oh your family was there for you, weren't they?' And they really wanted to be soothed that the family will be there. But we all know that in so many cases of acquired disability, your relationships break down and families are not there. And I think that it's become something where I don't even talk about it anymore because it's a myth*.

- *More awareness by others - There is little awareness of families and the public about people with ABI. There needs to be information and training (see previous points).*

- *No more discrimination - Discrimination is everywhere. We have shown that schools and colleges, workplaces, communities and services are made for the able-bodied. People with ABI are excluded as a result. People need to understand the social model of disability – It is society that disables us because it is not designed for us*[28]*.*

This is not for you.



Training Resources

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[28] It was also pointed out that *the regions really struggle* and there was systemic discrimination against people living in those areas in terms of service access and availability.

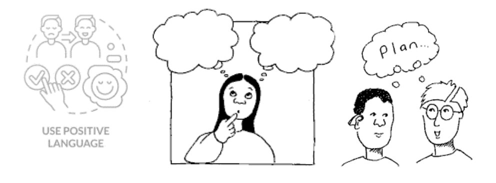
A number of other things were mentioned as being vital for people with ABI

- *Services and systems that do not discriminate against people with ABI and those with ABI and other identities and provide better access*[29]*.*

- *Multidisciplinary teams - There is a need to link up services across health, disability support and community*[30]*.*

Teams that work together and directed by the person

No discrimination. Respect for difference!!



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[29] *Recently I wanted to extend my (NDIS) plan and I spoke to my support coordinator and they said NDIS are gonna do a full on plan review and they won't give an extension to you if you ask for it. She said 'I'll ask for it and it will be fine'. And that that was a huge lesson learned - they would listen to her but not me. But really, that's been going on for years, you know, if you wanna get action, get someone else to speak for you, which is just so disempowering*; *Yeah, I'm not on NDIS because organisations wanted me to apply for services that I didn't need but would give them more funding. I've been told I was in denial because I didn't want a motorised wheelchair.*

[30] *There's no communication' between services*; *There is no such thing as having a multidisciplinary team…. How the hell do I find it?... But it's very difficult for us to source ourselves, so how the hell are so many other people gonna be able to do it? So there needs to be some communication between these disability services*.

- *Positive regard and respect from services and systems – People with ABI all have something to contribute; support that and in doing so support their identity and place in the world.*

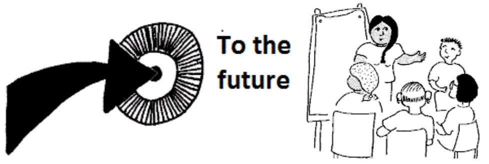
- *There needs to be a greater focus on supporting people with ABI around life skills and personal development to achieve their stated aims*[31].

- *Increase public awareness of ABI and make community and education spaces accessible. There should be no systems that exclude.*

- *Take the time to change the culture amongst the public and families through education and information. Back it up with services that support positive outcomes or they will continue to see people with ABI as 'a problem'. People need to understand the social model of disability.*

A better informed public

Accessible communities



My aims: Personal development and support

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[31] *Trying to be more employable, like education and training is part of that and it is often inaccessible*; *Even the Disability Liaison Unit [at a college] were trying to get me to hide some of my disabilities, and not list them because they said that some of them were more stigmatising than others… It was just too hard. And I had to drop out.*

Start with **MY** goals

- *Make sure all services and supports work with the person and their goals.*
- *Make sure we have equal access to health and disability support services.*

Equal access to support services

- *Make sure systems, services and supports are there for each person and not protecting themselves. This leads to confrontation and a system that is slow to respond.*

- *Discrimination is systemic*
    - *Communities, services and supports are not set up to cater for people with ABI. Schools and colleges teach people but exclude the needs of people with ABI.*
    - *Many agencies can be confrontational – such as Guardians, State Trustees and even disability services. They protect themselves but do not support a person's will and preference. There needs to be some independence to all of these organisations and they should be on the side of the person and the person only.*
    - *When services are not available you become more vulnerable to violence, abuse, neglect and exploitation.*

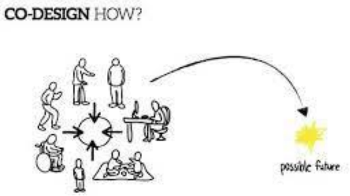
Exclusion, discrimination, confrontation and control
Inadequate services and supports can lead to violence, abuse, neglect and exploitation

The need for advocacy:

There is a need for individual and self-advocacy to protect rights and prevent discrimination

- *People need advocacy to ensure they have equal power in a system which is often too complex, confrontational and in which their rights are infringed.*
- *Many people with ABI do not have an understanding of complex things that are done or said quickly, and so their voices go unheard unless advocacy services have a role.*
- *The most vulnerable – people with ABI in prisons or those who are isolated or cannot speak for themselves are the ones most at risk and more attention needs to be paid to their human rights and to the services that will make them safe.*
- *There are far too few people with disability and ABI who are involved in the development of disability services or who design, produce and deliver services used by people with ABI.*

The most vulnerable people with ABI may be in jail, may be isolated or may not be able to speak up. They are more likely to experience violence, abuse, neglect or exploitation.



We need coproduction and codesign – services by people with ABI for people with ABI

Section 3 - Some final points the Disability Royal Commission should hear

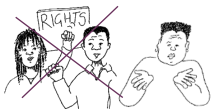
The importance of self-advocacy: participants felt particularly strongly that self-advocacy was vital.

- *Life has been fantastic because we're meeting like-minded people and we're all great friends.*

- *…it's so hard to have respect for yourself if you're not getting any respect from the outside world because then you don't feel like you deserve respect… we actually really need the support and the funding to support self-advocacy so that we can do self-advocacy.*

- *The loss of peer support groups and self-advocacy groups over the past few years is such a tragedy…. for both individuals and for the disability rights movement.*

No funding, no groups,
no rights, no voice



More funding is needed for self-advocacy.

We need our own
communities.

Earlier the downward spiral of rejection and exclusion was described. We have shown how this happens to people with ABI. As one person says

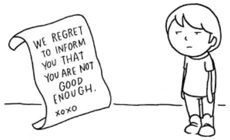
- *You know, there's so many things going wrong, so many things affecting us after injury, but it's the recognition of the life that we're sort of forced to live, which is the really bad part.*

The life people with ABI are forced to live prompted one person to say:

- *…but as everybody said, this is not the good life. It's just got worse as I've aged. It seems to get worse in the last 10 years… I dislike the world we live in very much. I only get through the day because I laugh and I'm just trying to see the very funniest things. And we're just going to maintain our own self esteem to do it. But I agree we're not supported, we're not recognised and there's nothing out there for us. Just try and enjoy my life as it is now and just see what the outcome may be in the future.*

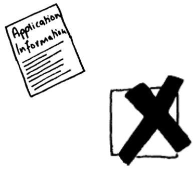
This quote was one of exasperation but highlighted the lack of support people with ABI feel. This can lead to isolation, to loneliness and to vulnerability, eventually leading to experiencing violence, abuse, neglect and exploitation. Lack of supports leads to the 'inevitability of vulnerability' and it differs to the extent such supports are in place, giving each person's experience a unique character.

The ‘inevitability of vulnerability’ linked to the lack of support.



Rejection by family & friends

Rejection by the community - "I'm on my own"



Inappropriate, insufficient, or no services and Centrelink payments

Lack of access to work, training and education - No personal development

Poor housing

Rejection, especially rejection linked to abuse, leads to isolation[32]. Lack of support and isolation lead to self-reliance. Personal coping when systems are discriminatory, leads to poverty, lack of resources to flourish and the reproduction of being invisible to the system. Once invisible, people are then vulnerable to abuse by others. This leads to them living in constant fear.

The following page describes the spiral of fear that people with ABI experience as a result of systemic abuse and exploitation discussed above.

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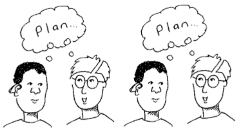
[32] Examples of disrespect: *I just want my existence to be respected* ; *I can't tell you the amount of medical professionals I've seen over the years and the lack of respect that I put up with and I've eventually got rid of them*; *Places like Centrelink say "Oh sorry you're not disabled enough to get the disability support pension*; *It's like I can't be bothered anymore dealing with that kinda crap… And I don't see why I should* ; and *Ableism is what stops me having a better life.*

Spiral of Fear

I fear rejection - I fear trying to be part of anything & being included. I don't know who I am any more



I fear having to start over... again & again & again

I fear being treated like a criminal and bludger. I fear the criminal justice system, interactions with police, the law, courts and prisons.

I fear not getting the services or supports I need

I fear not getting services and supports so I don't apply

I fear inappropriate services like being locked up or put in a psych ward

I fear having nowhere to live

I fear complaining so I don't

I fear losing my job and being struck off DSP. No dreams, I can't afford them

I am likely to be poor, to be unseen and unheard. And I can do nothing since this is not caused by me

I am therefore more vulnerable and feel rejected, isolated and unsafe

This makes me more likely to suffer violence, abuse, neglect and exploitation

Some final comments by the group were

- *People aren’t listening to your fears and concerns, and we then repeat them because we’re trying to understand it for ourselves and that’s really hard for anyone. And I think there is a lack of concern [by others] of us being heard.*

- *All of that, it’s all human rights. You know, people have the right to life and liberty, and freedom from torture. We have the right to opinions and expressions. And I feel like that we are just being discriminated against and having all of our rights sucked away and that we’re being treated like lesser human beings. So, all of this is a human rights issue.*