Relationships Australia®

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Online Submission

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Relationships Australia welcomes the opportunity to make a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This submission is made on behalf of our federation of State/Territory Relationships Australia organisations.

About Relationships Australia

Relationships Australia is a federation of community-based, not-for-profit organisations with no religious affiliations. Our services are for all members of the community, regardless of religious belief, age, gender, sexual orientation, lifestyle choice, living arrangements, cultural background or economic circumstances.

Relationships Australia has, for over 70 years, provided a range of relationship services to Australian families, including individual, couple and family group counselling, dispute resolution, services to older people, children's services, services for victims and perpetrators of family violence, and relationship and professional education. We aim to support all people in Australia to live with positive and respectful relationships, and believe that people have the capacity to change how they relate to others and develop better health and wellbeing.

Relationships Australia provides a range of services that support people who live with disability and/or have complex needs, including due to trauma. Some of our specialised trauma and family mental health services include our:

- Disability Counselling and Support service – For people with disability who have experienced violence, abuse, neglect and exploitation, and those affected by the Disability Royal Commission
- Redress Support Services for people contemplating or going through the National Redress Scheme
- Forced Adoption Support Services, which offers counselling, information and referral to those affected by past forced adoption practices
- Senior Relationship Services assisting older people and their families to prevent and resolve family conflict, plan for the future (including medical, health, financial and living arrangements), improve communication skills, make decisions that protect the interests, rights and safety of family members and reduce the risk of elder abuse.

These services support people by providing:

- person-centred and trauma-informed counselling, capacity building, mental health and transition support, and mediation,
- warm transfers to other support services if required, and
- information and referrals about other useful services.

We respect the rights of all people, in all their diversity, to live life fully and meaningfully within their families and communities with dignity and safety, and to enjoy respectful relationships. A commitment to fundamental human rights, to be recognised universally and without discrimination, underpins our work.

Relationships Australia is committed to:

- Working in regional, rural and remote areas, recognising that there are fewer resources available to people in these areas, and that they live with pressures, complexities and uncertainties not experienced by those living in cities and regional centres.
- Collaboration. We work collectively with local and peak body organisations to deliver a spectrum of prevention, early and tertiary intervention programs with people of all genders, including older people, young people and children. We recognise that some families need a complex suite of supports (for example, family support programs, mental health services, gambling services, drug and alcohol services, and housing).
- Enriching family relationships, and encouraging clear and respectful communication.
- Ensuring that services are accessible, including ensuring that social and financial disadvantage is no barrier to accessing services.
- Contributing its practice evidence and skills to research projects, the development of public policy, and the provision of compassionate and effective supports to families.

Notes on language Relationships Australia uses:

- where context allows - ‘service’ rather than ‘care’ to underscore the autonomy of people who receive aged care services; ‘care’ licenses paternalism and even ageism, and
- ‘user’ rather than ‘recipient’ because ‘user’ is more autonomy-friendly and active; ‘recipient’ is more passive. ‘User’ can also include a person’s loved ones and representatives.

Services relating to the DRC

Since December 2019, Relationships Australia has been funded across seven states and territories to provide Frontline Counselling and Support Services for clients affected by the Disability Royal Commission (DRC). During this period, we have provided counselling and support via face-to-face, video conferencing and telephone to people with disability, their families and others involved in the Royal Commission.

Our frontline counselling and support service focuses on the psychological and support needs of our clients who are impacted by violence, abuse, neglect, and exploitation, and works closely with a range of other support services such as disability advocacy services.

This submission will outline themes that have emerged and/or been observed throughout the provision of this service and other services across the Relationships Australia Federation. These themes emerge from the pervasive challenges which affect those living with disability throughout Australia. However, we do note that we write from a policy-focussed, provider's perspective; accordingly, there is a myriad of issues and perspectives from those living with disability that this submission does not reflect, but which are centred in the submissions made by those with lived experience.

Contents

Conceptual Framework

Social Model of Disability

This submission will interpret disability using the social model. The social model of disability recognises that ‘disability’ is socially constructed. Disability is a one-dimensional term used to illustrate medical abnormalities in comparison to a putative ‘normal’ population. The social model acknowledges the impact of impairment on individual experience, but sees ‘disability’ as a result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers (People with Disability Australia, 2021).

The social model of disability recognises that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others. Importantly, it acknowledges that any accommodations for impairment should be an *expected* incident of human diversity.

Relationships Australia understands disability through the social model, which informs how we provide our services and conduct our research and advocacy work. In accordance with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which marked the official paradigm shift towards the social model of disability, we believe that the issues that face people living with disability result from an ill-equipped social environment, rather than the impairment itself. Despite the paradigm shift, there are still many structural, attitudinal, physical and social changes needed to enable those living with disability to participate in society on an equal basis with others.

Relationships Australia’s work addressing loneliness

Relationships Australia has comprehensive expertise and experience in the loneliness space. We have clinical expertise supporting clients who experience loneliness and have conducted pioneering research which used the Household, Income and Labor Dynamics Survey (HILDA) data, to understand who experiences loneliness. Finally, we are the home of Neighbour Day, a social connection campaign that supports people to create connections that combat loneliness. While providing the Frontline Counselling and Support Services for the DRC, our practitioners have noted that experiences of loneliness and social isolation have been ubiquitous among clients.

Social model of loneliness

The core of Relationships Australia’s work is relationships. We work with people to enhance and improve relationships of all kinds, including among families (whether or not the family is together), with friends and colleagues, within communities and people’s relationship with themselves. Relationships Australia contextualises its work with a commitment to strengthening relationships between people and a robust commitment to human rights.

Accordingly, this submission refers extensively to emerging evidence indicating:

- the adverse impacts of social isolation and loneliness, which include increased risk of becoming a victim or perpetrator of abuse, as well as pervasive negative effects on mental and physical health, and
- the protective impacts of safe and healthy family relationships, and of social belonging and connection in both preventing violence, abuse, neglect and exploitation, and mitigating its impacts.

Relationships Australia believes that the connection between respectful relationships, human rights, mental health and loneliness is inextricable. As such, it is also important to establish an understanding of loneliness within a social model.

Loneliness is usually understood as a subjective state, a set of complex and upsetting feelings when an individual's social needs are unmet (distinct from the objective state of being alone or socially isolated) (Heinrich & Gullone, 2006). This distinction between social isolation and loneliness enables researchers to differentiate the phenomenon from other more objective social concepts, which are highly related but not mutually inclusive. While those who are lonely are not necessarily socially isolated, the experience of loneliness is indistinguishable from the social environment. Relationships Australia believes that the tendency to differentiate loneliness from the socially bound concept of social isolation has led to a more individualised understanding of loneliness, which has limited researchers' ability to examine the social environments that perpetuated loneliness.

A pioneering study investigating the social model of loneliness found that it was the social structures themselves which (dis)empowered people living with a disability, specifically, older cognitively impaired people, which ultimately led to social exclusion and loneliness. Traditionally there have been assumptions that the biological manifestations of cognitive impairment lead to a loss of social resources, as sufferers are unable to maintain their former social lives. Burholt and colleagues explored the effect cognitive impairment had on older people's pathway to loneliness, establishing new evidence that suggests that our social-structural understanding of disability significantly impacts social resources.

For example, attitudes of staff and public in facilities can influence whether or not a person continues to engage in social activities (Woods, 2012). Moreover, purpose-built dementia-friendly centres, which aim to increase opportunities for socialisation through enhanced social support to complete normal routine activities, are found to increase the life expectancy of inhabitants (Lin & Lewis, 2015). This research established that it was the social environment's treatment of the disability that limited social resources which, in turn, led to loneliness, rather than the biological experience of dementia that disrupted social abilities (Burholt, 2017).

Establishing a social model of loneliness highlights how the social environment, and its incumbent assumptions, leads to poorer mental health and wellbeing outcomes for those living with disability. Shifting the narrative away from impairment-thinking, the solutions to these interconnected issues become analogous. Interventions which focus on creating a more supportive social environment for all will have a positive impact in both spaces. Furthermore, the work occurring at all levels of government to address mental health, wellbeing, loneliness and suicide prevention should centre the voices and experiences of those living with a disability and acknowledge the particular environmental challenges they experience. Relationships Australia believes that to address the violence, abuse, neglect and exploitation experienced by those living with disability, we must acknowledge how social isolation, loneliness and the social environment contributes to these phenomena.

Themes

Pursuing autonomy for those historically denied it

While the right to live a full and meaningful life with dignity and safety is supposedly afforded to all, the significant barriers in work, study, sport, movement and everyday life for those living with a disability challenges their autonomy. Supporting a historically marginalised group to have choice and control over all aspects of their life is challenged by the ongoing and permeating experiences of violence, abuse, neglect and exploitation among those living with disability. While providing counselling and support services, Relationships Australia has noted the difficulty clients face when pursuing an autonomous life.

This is especially evident when providing person-centred counselling. The principles of person-centred counselling are:

- to facilitate clients to self-actualise, by supporting the client to identify and utilise their strengths,
- achieve personal growth,
- relationship growth and autonomy (Corsini and Wedding, 2000).

Self-actualisation can include attaining sociability, being open to experience; being trusting and trustworthy; and being curious, creative and compassionate. The experiences and past traumas of the client group make these goals very challenging and, in some cases, have required practitioners to develop a different set of measures to evaluate the outcomes of the service.

Case Study 1:

Stephen*, a practitioner at Relationships Australia working in counselling and support services for the DRC was in a session with Ishmael*. They had spent time identifying needs for Ishmael, exploring ways he could improve his current conditions, including making phone calls to various service providers to arrange new service and altering existing ones. Stephen spent time with Ishmael discussing his requirements and goals before making the calls. When it came time to make them, Stephen offered Ishmael the phone. He was taken aback, as when interacting with services and advocates in the past, he had never before been offered the opportunity to do something like this for himself, despite having the communication capacities to do so. Stephen says this kind of ‘offering up of autonomy’ is common among clients he has seen; something which is compounded further by their experiences of complex trauma.

*Names have been changed to protect identities

Practitioners report that a significant portion of the work involves educating clients on their rights. The life-long experience of having their decisions made for them means that when completing ostensibly 'every-day' tasks, clients feel dependent on services. When contextualised within client's experiences of violence, abuse, neglect and exploitation at the hands of institutions and services, this 'handing over of autonomy' becomes especially concerning. To counter this, practitioners report spending significantly longer in initial sessions gaining the trust and developing respect.

Further, this loss of autonomy in experiences with past institutions and services requires practitioners to spend significant time exploring and explaining the goals of the DRC, including the potential changes that may come about as a result of the DRC. Although many clients have heard of the DRC, educating clients on their rights, supporting them as they process the trauma associated with how these have been violated in the past, *and then* supporting them to make a submission if they choose to do so, is a time-consuming, sensitive and complex process. It is, nevertheless, a vital process if the DRC is to achieve its aims, including through acknowledging and responding, in meaningful ways, to past violations of people's rights.

All of these issues are exemplary of the challenges associated with implementing a never-before-funded contract. When serving a vulnerable and underserviced population, a significant proportion of time is spent on:

1. Needs assessment – a lot of the work revolves around meeting basic needs. These can include things such as safe and secure housing, and often involve referrals. They must be addressed before moving onto other issues.[1]
2. Education and support – emanating from a Royal Commission which seeks to address the violation of human rights, the work requires practitioners to educate and support clients on concepts that they have historically been denied.
3. Establishing and understanding the unique communication needs across a vast and diverse population of almost 4.4 million Australians (AIHW 2020) – for example, there is no exact translatable word for disability in Aboriginal languages. This means disability is discussed without grouping together vast populations with different needs. Practitioners were required to find new ways to reach clients and discuss their issues that did not priviledge the Western concept of disability.

These issues will be addressed further in the 'structural barriers' portion of this paper.

The need for clients to self-advocate

The need for self-advocacy is enshrined as a key component of the disability framework. For example, in the Issues Paper on Safeguards and Quality, the Royal Commission outlined self-advocacy as an informal safeguard (2021). As discussed, a loss of autonomy is a pervasive experience for those living with disability; yet self-advocacy is an expression of autonomy, in that it empowers those living with disability to communicate their needs and desires. While

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[1] This is true across many of our services supporting clients with significant levels of trauma, including, for example, those experiencing domestic and family violence, where practitioners must ensure that basic needs such as food and shelter take immediate priority before addressing needs that are more therapeutic.

self-advocacy provides an important opportunity to gain autonomy, clients with disability can face several challenges that create barriers to advocating for themselves, including:

- communication challenges
- physical barriers
- systemic and structural barriers, and
- social and environmental barriers.

While we support empowerment as a foundational tenet in service delivery, systems that rely on people with disability to self-advocate for more quality services and formal safeguards, engender a system where violence, abuse, neglect and exploitation take place. The outcomes of this approach are evident in the NDIS, a scheme which was established to address the substantial emotional, physical and financial costs associated with living with a disability, but for many, has further burdened them.

The NDIS encourages autonomy, as it allows those receiving the funding to select their providers and tailor their support to their unique needs (May et al., 2017). In some ways, it reflects a shift in focus from 'one-size-fits-all' thinking, recognising the diversity of people living with disability. However, it is also a move towards dedifferentiated policy, which can lead to a lack of accountability by services and a loss of expertise within funded services (Bigby, 2017). Service providers who have no direct expertise in, or knowledge of, disability-specific issues are engaged as providers (Bigby, 2017). While this encourages choice and independence for those living with disability, the very nature of disability makes finding the 'right' service challenging for many (May et al., 2017). This free market approach also removes the responsibility of client outcomes from service providers. On paper, this seems like an effective approach to move away from the cycle of funding and micro-evaluation of service providers. However, in a space so defined by violence, abuse, neglect and exploitation, the marketisation and commodification of welfare does not address the systemic issues which led to the historic lack of choice and control for those living with disability. This approach may at times overestimate the capacity some individuals have to advocate for themselves to access the appropriate services and shifts the burden onto them to regulate providers. It assumes that:

- the person living with a disability and/or their carer has the capacity, resources and will to advocate
- the person living with a disability and/or their carer is aware of their rights and their right to defend and safeguard them
- the carer has the best interests of the person living with disability at heart, and
- the systems they are advocating to have the capacity, resources and will to listen.

Case Study 2:

Sharon*, a person with disabilities from a rural community, presented to our service. She has serious mobility issues, functional issues with balance and severe chronic pain. She is identified as having a 'falls risk'. She has an NDIS plan, but due to the complexity of the NDIS rules, has not obtained many crucial supports and modifications needed to remain safely in her own home. She has multiple falls at home, two of which resulted in her being knocked unconscious, and other falls that left her with a broken leg and a broken foot in four places, all for want of simple safety rails and other basic safety improvements. Her case is multi-layered and is being dealt with by NDIA. Her most recent planner breached client confidentiality, providing personal information to a private provider without client consent.

Sharon* complained to NDIA about this breach, requesting a new planner. The NDIA responded that she must continue with the same planner. The client then sent a complaint with a written request for a new planner. Neither that complaint nor the request was acknowledged. At this point, she nearly gave up trying to communicate with the NDIA Complex Support Needs Team controlling her plan. In the meantime, she continued to experience numerous worsening falls at home because she has none of the safety modifications which were described clearly in her NDIS Plan.

The client has AT mobility equipment in her plan budget, which has not been granted. Her support practitioner at Relationships Australia rang the local LAC to ask if the client could be referred there instead. The answer was negative: if the NDIA decides to manage her plan because they judge her to be too complex for mainstream NDIA, she has no choice but to stay with them. The client says that although she thought NDIS would be "wonderful" for her, she wishes she had never heard of it because of all the frustrations it has caused her. As her condition worsens due to NDIA refusal to accept her two safety modification submissions, she feels neglected by NDIS/NDIA. These are the very agencies set up to support her NDIS goals: to remain in her own home, with safety and functional independence, being as active and safe as possible.

Case Study 3:

Betty* has been using a TTY (Tele-Typewriter) for phone communication. However, since the installation of the NBN, Betty* has been encountering an issue with their phone, unable to make or receive phone calls. This has left Betty* vulnerable in different aspects:

- Unable to make or follow-up for medical appointments
- Unable to communicate with friends and family, making maintaining a social life challenging
- Finding about family or friends passing away in the newspaper, because people cannot communicate with them via phone
- Vulnerable to medical emergencies - the TTY is connected to the Emergency services and client has a medal to press if victim of fall or dizziness. However, the ambulance service were considering removing the service, as they were not able to confirm call via phone.

Case Study 3 continued:

This issue has been ongoing since October 2019.

A support worker at Relationships Australia has been trying, for over a year (since August 2020), to address the TTY issue via the National Relay Service and through the NBN and Telstra, without any improvement or resolution. Telstra were sending new TTYs without clear assessment of the issue.

The support worker organised a soft referral for the client to the ADAI (Advocacy Disability Services). A disability advocate has been in constant contact with Telstra to organise an in-depth assessment, however the same pattern occurred (Telstra sending new phones), without improvement.

Eventually, the disability advocate escalated the matter to the Ombudsman and to the Premier. Telstra admit that they do not know how to resolve the issue.

The client has been allocated a new phone and is able to receive voicemail, but still no phone calls. The advocate said that another technician will visit the client, in the presence of the advocate, to try fix the issue, and the advocate will continue to engage in communication with the relevant services to push for resolution of the issue.

When people with a disability are faced with bureaucratic quagmires, the requirement to self-advocate assumes equity in ability to navigate the processes and structures of bureaucratic organisations. In this case, and many others, people with disability are forced to live without essential services until they obtain support from organisations or individuals with the capital to negotiate bureaucratic processes. The paradox found within the bureaucratic orientation conceptualises disability as a “lack of function resulting in an inability to keep the rules” that is then managed by the imposition of further rules that need to be kept (Titchkosky, 2020). Rather than acknowledging and creating space for the disruptive difference that disability can represent, in order to receive necessary supports to gain independence, those with a disability must again rely on others to engender their own autonomy.

Case Study 4:

After working with the behaviour practitioner, some staff were able to better understand Jade’s* history and behavioural triggers and respond in an empathetic way that promoted greater mutual respect. In an environment of greater trust, Jade* began to demonstrate more consistent maturity and independence. For Jade* to reach her goals and full potential, she will need to consistently source staff with the appropriate level of skills and training. In a regional area this will be unlikely to occur, and Jade* remains at risk of being triggered and re-traumatised at regular intervals by her own funded support staff.

Case Study 4:

Jade* experienced childhood abuse and neglect. She had a disrupted childhood living with various family members. There are references to sexual abuse in the documentation but details have not been disclosed. She was diagnosed with an intellectual disability at around 7 years of age after teachers flagged her learning difficulties at school.

At around 19 years old, while accessing block-funded respite, Jade* disclosed to staff that she was fearful to return home due to her stepfather's threats of violence. She was provided with short-term accommodation and a SACAT application was made for guardianship to prevent further violence and financial exploitation. She has been in short term accommodation for around three years pending the outcome of assessments and an NDIS determination of her ongoing accommodation support funding needs. The support provider manages the house that she lives in. Jade* has a goal to live in her own house so does not have a sense of permanence in the current residence. It is likely that, once her funding comes through, she will continue to live in the same house and have the lease transferred to her name – managed by Public Trustee. Sourcing diagnostic assessments and therapeutic supports in a regional area is difficult as most professionals are based in the city, several hours away. For those who do provide local services, there is a waitlist of 3-6 months. Often, a provider will have moved on before the therapeutic supports can commence and a new provider has to be found, starting a new wait time.

Further undermining this supposed autonomy, many people on the NDIS require their funds to be managed by a third party, effectively reducing the element of choice and control the NDIS was set up to provide. There is a lack of accountability for those servicing an extremely vulnerable group and within a capitalist market, the commodification of care "tends to drive labour cost-cutting and encourages low-wage strategies for paid care workers and low-quality care" (Macdonald, 2017).

The NDIS uses insurance principles rather than a welfare model of disability. Part of the insurance model was aimed at supporting the NDIS to act at the systemic level, as well as fund individual support needs (NDIS, 2019). The NDIS sees this as especially important for their ability to support those who do not meet the criteria to become NDIS participants, by providing information, linkages and capacity building support (2019). Despite this, clients report experiences of violence, abuse, neglect and exploitation in their experiences with (or without) the NDIS, especially in relation to diagnosis-based funding models.

Practitioners report that many of the clients visiting our services have faced structural challenges accessing the services in order to obtain a diagnosis. These include:

- Lack of access to services in regional, rural and remote locations,
- Inability to pay for the out-right costs,
- Inability to obtain a diagnosis for rare and complex conditions,
- Age limitations limiting NDIS access, and
- Fatigue with the system requiring case management and specialised supports in order to navigate the challenges associated with gaining a diagnosis and completing an NDIS application.

Establishment of the NDIS was an attempt to incorporate those living with disability into the mainstream, without acknowledging the history of trauma at the hands of services, nor the enormous and continuing environmental barriers which limit those living with disability from engaging with a service. In reality, there has been little support for the clients (or the services) to access or create more accessible services. Although the NDIS claims to move away from diagnosis-based funding, the almost universal need for a diagnosis in order to qualify for the NDIS leaves those without one with little practical support, beyond the 'information, linkages and capacity building' the NDIS states that it provides.

Making the service industry more accessible

The funding model for the provision of counselling and support services for the DRC was intended to equip organisations with the resources necessary to ensure their services were accessible, and to upskill staff to meet the needs of the diverse cohort of clients with which the DRC is concerned. A pivotal challenge faced by our teams has been sourcing training and upskilling programs that are both trauma-informed and disability focussed. While our teams have been able to access some excellent training (as outlined in the 'Access Barriers' section of the submission), our search for such programs has highlighted the shocking lack of training available. Given the wide variety of mainstream services involved in the provision of NDIS services, we consider that to appropriately provide support to people living with disability, all allied health practitioners should have received appropriate training in relevant domains.

Relationships Australia believes this lack of appropriate training is illustrative of a system-wide lack of support for those living with disability and providers alike, which ultimately leads to further violence, abuse, neglect and exploitation. Relationships Australia believes that, while the NDIS is an attempt to provide those living with disability choice and control, the lack of appropriate training to prepare the workforce has forced users to engage harmful service providers. Those with disability are then expected to re-locate to more appropriate services or self-advocate with their current providers. Firstly, this assumes there are alternative services to go to, which is not the case for those in certain geographical areas, those facing funding issues or those fatigued by the need to re-locate and re-tell their story, which can be re-traumatising. If they choose to stay and advocate for change, it assumes the capacity, resources and will on the part of the user and/or their carer, *and* an assumption that mainstream services have the capacity and will to improve their accessibility. Relationships Australia believes this lack of appropriate training directly undermines services' ability to provide trauma-informed and disability focused services to people needing them, further limiting the pool of available appropriate supports for people living with disability.

Finally, this lack of training has made it difficult to ethically refer clients on, as it is difficult to locate therapeutic support that meets the minimum standards. Compounding this obstacle, Relationships Australia is unable to support these clients in the long-term due to funding limitations. This leads these traumatised, neglected and under-funded groups, with whome our services have just spent significant time and effort creating trusting therapeutic relationships, to the precipice of yet another support cliff.

The Education System

Relationships Australia acknowledges that the issues facing those living with disability within the education and learning sectors are rife, exemplified by Issues Paper 1 on this topic. Throughout our services we have witnessed a myriad of issues which our clients have encountered in their dealings with the education system. By way of example, this submission focuses on the issues which limit a person's ability to self-advocate within the education system, including:

- The lack of external bodies and frameworks for identifying, disclosing and reporting violence, abuse, neglect or exploitation in education and learning settings, making advocating against these difficult, time-consuming and exhausting. This means those families experiencing multiple and intersecting challenges are exposed to overlapping forms of discrimination and marginalisation, but must self-advocate through fragmented systems in order to achieve change.
- When these families are inevitably fatigued by this process, they are threatened with cuts to funding, exclusion from activities, segregation, suspensions and expulsions, which ultimately contravene the child's right to equal education and future prospects.[2]
- The parallel burdens faced by families already experiencing domestic and family violence and navigating the family law, family violence and child protection systems. For example, there are instances of the Family Court ordering ongoing contact between child/ren and their father (who is also the perpetrator) or risk consequences, while the child protection system threatens her with sanctions if she allows that contact. While proposed reforms are seeking to minimise those inconsistencies, for those living with, or parenting a child with a disability, managing these conflicting and systemic barriers represents yet another pressure and limits the capacity of the parent/carer to self-advocate within the school system (for more information please see Case Study 5).

Relying on self-advocacy, or advocacy by carers, as a safeguard in a system rife with violence, abuse, neglect and exploitation makes assumptions about equitable capacities across the variety of people living with disability. It presumes autonomy and promises choice, without acknowledging the myriad of structural and systemic barriers limiting those living with a disability from accessing mainstream services and institutions. Ultimately, those who have the capacity to self-advocate, or the support systems to do so, are fatigued and exhausted by the process and often further traumatised, limiting their ability to advocate when they face future similar challenges. Those who cannot self-advocate, especially those living with comorbidities or who are socially and financially disadvantaged in other ways, are denied access to resources and opportunities and fall further behind.

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[2] This contravenes the Convention on the Rights of the Child, the international human rights instruments to which Australia is a party.

Case Study 5:
Katelyn*, a practitioner with Relationships Australia, has seen a pattern in families with single mothers caring for one or more children living with Autism Spectrum Disorder (ASD), often in primary school aged children (years 6 and 7) experiencing domestic and family violence (DFV). Katelyn* has noticed a universal response from the education department, with regional manager conducting spot (unannounced/uninvited) home visits to the child's home. Clients have reported that they are criticised for their mothering and are told to 'just tell the child to just go to school and [do what you need to to] get them there'. Mothers then report the child to be feeling highly anxious and invisible, which is compounded by their need to learn how to communicate these feelings with the people around them [in the school environment].

The parents must then try find a staff member at the school who will support the family's strategies and understand the barriers and challenges they have getting to school. The pattern can be outlined as below:

1. Child not attending school
2. There is an attempt to make a plan to get to school but it has not worked yet, or is not working
3. Someone from the Department will turn up at the child's home with no warning, and interrupt the child's 'safe space', which reinforces untrusting relationships with the school for both child and family
4. Parent must then find someone to help advocate for NDIS funding and a staff member within the school who will enable coordinated support
5. If a child gains an NDIS plan, it is then the parents' responsibility to find an ASD trained support worker available to help with transitions to school - this is extremely challenging as it is a very specific skill-set.
6. The parent must then negotiate between the NDIS and the school to find a suitable outcome
7. ASD requires a united and structured response, and when there are disagreements between institutions, this compromises the child's development and place the responsibility of finding a solution on the parent-carer, who in some cases, is already navigating DFV as a single parent.

Balancing the tension between autonomy and safety and protection

While providing the counselling and support services for the Disability Royal Commission (DRC), Relationships Australia has noted a critical tension between providing clients with autonomy, while also ensuring safety and protection from these violations.

Relationships Australia has spoken extensively about concerns relating to the quality and safety in aged care and the use of restrictive practices in these settings.[3] We believe that many of the same principles apply in the disability sector. As described by the issues paper addressing the topic, restrictive practices are often understood as a 'disability-specific' form of violence (DRC,

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[3] See, for example, our submission (30 August 2019) to the Commission into Aged Care Quality and Safety and our Submission (4 September 2019) to the Inquiry into Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019 - Restrictive practices.

2020). When considering the safety and protection of those living with disability, these should always be balanced against a system that prioritises autonomy by:

- supporting the quality of life of users, including through embracing dignity of risk, according to their individual wishes, preferences, values and capacities
- establishing frameworks which favour supported-decision making rather than substituted decision-making
- providing external bodies and frameworks for identifying, disclosing, reporting and responding to violence, abuse, neglect or exploitation to provide safety and protection when needed

This must be supported by a service sector which:

- empowers users to express their individuality and draw on their own strengths/abilities as they see fit
- offers high quality services that support users to access their preferred providers, in place-based and culturally safe formats
- enables real choice with adequately trained workforces who are remunerated fairly and appropriately within a system that minimises employment precarity
- listens and centres the voices of those with disability, who are the experts in their own lives, experiences and needs, and
- for those living in care facilities – these should aim to be 'residential', by providing a home, not an institution, allowing freedom of movement within and outside the facility, independence, choice of activities, ability to attend activities that they enjoy, and engage with risk.

Buttressing this, is a legal framework for the human rights of bodily integrity and personal liberty. In common law, it is well-established that all people have a right to bodily integrity.[4] This right has been vindicated, for centuries, in criminal and civil law and remains good law in Australia. This right is based on the primacy of the moral principle of autonomy and finds expression, too, in

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[4] See *Department of Health and Community Services v JWB and SMB (Marion's Case)* (1992) 175 CLR 218. In *Re Marion*, several different terms are apparently used to describe this interest: right to bodily integrity (joint judgment, 223, 254; McHugh J, 311), principle of bodily inviolability (joint judgment, 223, 235, 249), principle of personal inviolability (joint judgment, 224), right to personal inviolability (joint judgment, 253, 254), right to bodily and personal integrity (joint judgment, 254), the law's protection of physical integrity (Brennan J, 265), the law's protection of physical integrity required to protect a person's unique dignity (Brennan J, 266, 267), personal integrity (Brennan J, 267, 273, 274, 284), physical integrity (Brennan J, 267, 274, 277), right to physical integrity (Brennan J, 268), human integrity (Deane J, 303), autonomy with respect to one's body (McHugh J, 309), right to control and self-determination in respect of one's body (McHugh J, 309). See also *Pratt v Davis* 79 NE 562 (1906), *Mohr v Williams* 104 NW 12 (1905), *Rolater v Strain* 127 P 96 (1913), and *Schloendorff v Society of New York Hospital* 105 NE 92 (1914). In these early twentieth century cases from the United States of America, plaintiff-patients successfully complained to courts that what had been done to them by their doctors was not the procedure about which they had been told, and to which they had consented. The cause of action relied upon was battery, or trespass to the person, and the courts upheld the complaints on the basis that a surgical operation was assault unless preceded by the consent of the patient. In *Schloendorff*, Justice Cardozo recognised a patient's right to determine what would be done to his or her body (at 93).

international human rights instruments to which Australia is a party.[5] For present purposes, this right operates so that lawmakers who wish to permit, to any degree, the use of restrictive practices must take as their starting point that people cannot be subjected to physical or chemical restraint without lawful authority. That authority ought not, because of the gravity of impinging on the right to bodily integrity, be exercised lightly (Williams, Chesterman, Laufer, 2014).

Similarly, personal liberty, the ‘bedrock value’ which is ‘the birthright of every individual under the common law’ can ‘only be restrained where this is authorised by law.’[6] Personal liberty has long been vindicated at common law through the writ of *habeus corpus* and the tort of false imprisonment.[7]

Relationships Australia agrees that

> *Every person is entitled to respect under the fundamental principles of dignity and personal integrity that underpins the legal framework. They do not lose this dignity or right to personal integrity because their capacity is diminished. Rather, the impairment calls for a deeper reflection of what is required on the part of those who have capacity to properly uphold both values (Williams, Chesterman & Laufer 2014).*

Disability should not, in any way, diminish the entitlement of a person to enjoy all the human rights that attend on personhood. Rather, impairment requires additional frameworks and structures to support the fundamental principles of dignity and integrity within the spectrum of human diversity.

Case Study 6:

Daniel*, who lives with cerebral palsy, was experiencing abuse from his parents, while also often being called on to provide financial support to the family in way of paying the families utility bills as well as rent due to a parent’s gambling addiction.

After leaving the family home, Daniel* was placed into several accommodations which were paid for by his NDIS funds. This included 24/7 care in a group home. His experience living here was extremely distressing. The young person reported that living in the group home was restrictive, as it did now allow him any personal space and also impeded on his goals to live independently with limited support. Daniel* felt that he did not require this level of support and was placed here due to a lack of alternatives.

The costs of 24/7 care consumed all Daniel’s* NDIS funding, which amounted to $80,000. Once the funding had expired, Daniel* was asked to move out. Since moving out of the 24/7 care, Daniel* has successfully gained accommodation in a rental property, however is currently waiting for further NDIS funding. At the time of writing, Daniel* is still waiting for an NDIS review.

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[5] Including the Convention of the Rights of Persons with Disabilities, the Convention on the Rights of the Child, the International Covenant on Civil and Political Rights, the Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the International Covenant on Economic, Social and Cultural Rights.

[6] *Antunovic v Dawson* (2010) VR 355 at [195], per Bell J.

[7] See, for example, *Darcy v State of NSW* [2011] NSWCA 413; *State of SA v Lampard-Trevorrow* (2010) 106 SASR 331.

Access barriers

Providing equitable access to mainstream services is integral to the social inclusion of people with a disability. Relationships Australia is committed to creating an accessible service for all Australians. As previously mentioned, the Relationships Australia Federation has taken the opportunity provided by the counselling and support funding to upskill a significant portion of our staff to ensure that a client's whole journey through our service streams, and anywhere we may refer them to, is positive. Some of these trainings include:

- Mentalisation Based Therapy (MBT) Therapy – Skills and strategies
- Key Word Signing – Introductory course
- Sexuality and Disability – One day workshop on disability and sexuality
- Working with Complex Communication Needs – facilitated by a speech pathologist who specialises in alternative and augmentative communication
- Maven Training – Understanding disability rights and addressing attitudinal barriers people with disabilities experience

We have also taken measures to minimise barriers to entry, including by increasing the physical and virtual accessibility of our office spaces, as well as the provision of online, over the phone and in-person services and mixed modality services, including group-work where appropriate. We have also used funding to create videos, animations and graphics, which introduce the client to the team and the space before they visit, as well as plain English service handbooks and consent forms, plain English resources on key issues such as trauma, how trauma presents, the importance of good mental health and getting help.

The broad nature of 'disability' has provided space for creative service provision and solutions to entry barriers. Despite this, we recognise that creating truly accessible services for the wide variety of disabilities that people experience is an ongoing responsibility, not a one off, 'set and forget' box to be ticked. We also acknowledge that the social services industry, and mainstream services in particular, have often been the root-cause of violence, abuse, neglect and exploitation of people living with a disability and therefore have an ongoing obligation to upskill and adjust service delivery as appropriate.

Some of the barriers our client cohort has reported through their experiences with the broad service industry include:

- Unaffordable services
- Excessive wait times
- Physically inaccessible buildings or buildings far from public transportation
- Practitioners and/or service staff with little experience supporting people with disability
- Practitioners and/or service staff with limited forms of communication or lacking experience in and access to assistive technologies
- Practitioners and/or service staff who are not trauma-informed, who stereotype their clients or harbour discriminatory, stigmatising or prejudiced beliefs
- Policy barriers, such as a lack of employees with disability, lack of access to programs, services or benefits due to eligibility criteria

- Restrictive scheduling, lack of communication pre and post appointment, insufficient time set aside for procedures – acknowledging the additional time clients require
- Culturally insensitive service provision
- Excessive paperwork, especially in relation to the NDIS
- Complex cases which require case management and warm referrals
- Re-traumatisation through repetitive and exhaustive in-take processes

The population we are working with are highly traumatised that is not the exception it is the rule and services and systems need to be accessible and currently they are not.

\- ***Practitioner, Relationships Australia***

Many clients need intensive case management, and a lot of their distress comes from the processes around accessing services such as NDIS. I have recently worked with a carer suffering grief and loss of a loved one who is now triggered by paperwork from applications and re-applications for NDIS funded support.

\- ***Practitioner, Relationships Australia***

The majority of [my clients] live with psychosocial disabilities coming from trauma. This impacts their ability to participate in supports and services because of requirements such as filling out paperwork. I have had some clients who express feeling dehumanised and triggered when filling out paperwork…This puts people into categories and from past experiences in institutions and government services, people feel their rights are not protected. I believe many people are not accessing the service, as they know we operate under mandatory notification and law. Clients who live with significant complex trauma, and due to the nature of violence and abuse [they have experienced] clients have barriers to contacting or using mainstream systems such as the police.

- Practitioner, Relationships Australia

Case Study 7:

Zĭhán* has self-diagnosed herself with a social phobia, which is a huge barrier to accessing services. All services have triage and intake processes that present as a barrier. Although Zĭhán's* phobia is extremely limiting, her practitioner reports that this is not an exception, but a rule for the population they are working with. The high-level of trauma at the hands of services and systems makes accessing essential services a challenge for most clients, meaning many present with a myriad of issues. As such, most clients need intensive case management, and a lot of their distress comes from the processes around accessing services such as NDIS. When this is confounded by experiences of grief and loss, complex trauma and abuse, the paperwork from applications and re-applications becomes a trigger.

Aboriginal and Torres Strait Islander Peoples

Aboriginal and Torres Strait Islander Australians experience higher rates of disability than non-Indigenous Australians. In 2015, the Australian Bureau of Statistics (ABS) found 24% of Aboriginal and/or Torres Strait Islander people identified as having a disability, compared to 17.5% in non-Indigenous households. By 2018–19 that figure had risen to 27% (Australian Indigenous HealthInfoNet 2020). The survey excludes people living in nursing homes, cared-accommodation and Aboriginal people living in very remote areas and discrete communities, so the numbers may be much higher (Creative Spirits, 2020). Additionally, First Nations groups do not have a general word describing the concept of disability, which can result in under-reporting.

Despite this, Aboriginal and Torres Strait Islander people access services at lower rates (Australian Human Rights Commission, 2015). Research finds that Aboriginal and Torres Strait Islander people with disability are often cared for within their extended family, rather than by service providers. This is true across remote, rural and urban Australia (AbSec 2020). This, coupled with a legacy of fear and mistrust of services, can place pressure on kinship systems and pose a barrier to receiving other support for those who would like to.

Research shows that many Aboriginal and/or Torres Strait Islander people with disability find that:

- They are generally not excluded from their communities
- Disability may be seen as 'payback' for a past wrong doing, or may be seen as something special
- Independence may not be seen as a major issue for some
- Disability may be viewed as a family or community topic rather than a personal one
- Disability awareness is highly variable across communities
- A person may be identified and named after their disability[8]

Relationships Australia believes that Aboriginal and Torres Strait Islander peoples with disability should be afforded the same rights as other Australians. This includes the right to choose between Aboriginal Controlled Organisations (ACO), ACO and non-ACO specialist disability services and mainstream services. We believe that by focusing on the right to choice,[9] people who live with disability, who also identify as Aboriginal and/or Torres Strait Islander, are not forced to choose between services which cater to different aspects of their identity. Relationships Australia also recognises the historical traumas caused by mainstream services to people who live with disability who also identify as Aboriginal and/or Torres Strait Islander. We believe that any services for Aboriginal and Torres Strait Islander peoples with disability, especially mainstream and non-ACO specialist disability services, must continually work to centre the importance of Country, culture and community.

Initially, while providing counselling and support services for the DRC, Relationships Australia has found that, especially in rural and remote locations, there was little awareness of the DRC

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[8] Much of this information was taken from the Australian Indigenous Health Infonet website http://www.healthinfonet.ecu.edu.au/related-issues/disability/reviews/disability-withinthe-indigenous-community, as well as the Creative Spirits analysis https://www.creativespirits.info/aboriginalculture/health/aboriginal-people-with-disability

[9] The right to choice is protected by Article 19 of the CRPD.

and its purpose. In response, our service providers engaged in networking efforts with other DRC and disability service providers. Together, they embarked upon roadshows around regional, rural and remote areas to raise awareness their services, and the DRC. Elsewhere, we found that in rural areas Aboriginal and Torres Strait Islander peoples have been hindered by the need for outreach services, which limit choice of services. Their only alternative is to travel off Country to a regional centre.

Throughout service provision, Relationships Australia has employed peer support workers who also operate as Aboriginal outreach officers. The combination of lived experience with connections to the community has engendered a sense of trust and knowledge that has been indispensable to the team and clients alike, as there are many clients who benefit from access to both services.

Our teams have also drawn upon expertise in other areas of the organisation, such as those who work with survivors of the Stolen Generations, to establish specific trainings to upskill staff across the organisation through multi-day workshops. These communities of practice have supported the entire organisation to become more inclusive for Aboriginal and Torres Strait Islander peoples with/or without disability. For these reasons, and many others, the teams providing the counselling and support for the DRC have received feedback from across the organisation about the enormous effect providing this service has had on increasing knowledge about disability.

Relationships Australia believes that in order to provide accessible and inclusive mainstream services for Aboriginal and Torres Strait Islander peoples, they must be central to conception, design, delivery and evaluation. We recommend that any service provision arising from the DRC should engage in authentic co-design, with space and funding for innovative and flexible responses, or risk low uptake and further marginalisation.

Regional Issues

All of the above issues are exacerbated in regional, rural and remote locations. While providing outreach services, practitioners have reported a lack of choice, limited accountability and pervasive homelessness as a result of the lack of services. For example, a practitioner in Broken Hill reported that locals report little choice when selecting providers. Clients state that the services tend be business-focused rather than centering the needs of the individual, something which is difficult to combat due to the lack of alternatives. Many people believe they are being taken advantage of but have nowhere else to turn.

Another practitioner spoke of their client’s inability to find ongoing employment due to discrimination or unfair dismissals. They felt these issues disproportionately affected those in regional locations due to:

- increased stereotyping and stigma,
- limited alternative options (forcing the client to ‘put up with’ the abuse), and
- reputational risk affecting future employment and additional costs associated with fighting unfair dismissals in regional locations (such as limited access to advocacy, travel costs and loss of work).

In this case, while the client was aware of their rights, this awareness proved insufficient as the services needed to exercise those rights were inaccessible.

Another outreach officer reported on the ‘gap locations’, such as Murray’s Beach, South Australia. Based on selection criteria, residents of this location were considered too close for outreach, despite a lack of access to local services. In cases such as this, there is little acknowledgement of the challenges clients face in travelling to obtain services, and for many, travel simply is not possible.

Providers report that there is little recognition, through funding and accountability measures, of the significant challenges in serving regional, rural and remote communities. For example, a practitioner located in the Perth servicing the Peel region of Western Australia conducts monthly outreach trips to remote areas. The travel time cannot be captured or reflected, no-shows cannot be replaced, and limitations on scheduling (due to the realities of outreach) makes the service less accessible. Face-to-face services will continue to be needed in these communities as online service delivery is not a panacea for population dispersal.[10] Burnout is also a significant concern – especially given the additional challenges presented by the 2019-2020 bushfire season, which disproportionately affected regional areas, and the ongoing pandemic.

People from Culturally and Linguistically Diverse Backgrounds

Balancing the importance of mainstreaming disability with the need to provide tailored services for groups with intersecting vulnerabilities is of particular concern when planning, designing and providing support for people from culturally and linguistically diverse backgrounds (CALD). CALD refers to a group as diverse as the term ‘living with disability’. As such, ensuring access, as well as adapting services to specific needs is neither a simple nor a static task. People from CALD backgrounds face difficulties in accessing information, isolation and difficulty in connecting with services that meet their cultural needs. Some of the specific issues faced by our client cohort include:

- Obtaining bilingual carers, advocates and other supports, especially in relation to the NDIS
- Lack of awareness of the DRC or associated services due to a lack of outreach or language-specific resources explaining the DRC and its role
- Language barriers and lack of culturally appropriate services when practitioners attempt to refer clients
- Navigating cultural stigmas around disability as well as stereotypes in the general community, and

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[10] Relationships Australia has consistently advocated for greater digital inclusion, including in the recent consultation by the Australian Communications and Media Authority on Consumer vulnerability: expectations for the telco industry. We also note the 2020 digital inclusion index findings in relation to regional and remote populations. See Thomas, J., Barraket, J., Wilson, CK., Holcombe-James, I., Kennedy, J., Rennie, E., Ewing, S., & MacDonald, T (2020). *Measuring Australia’s Digital Divide: The Australian Digital Inclusion Index 2020*, RMIT and Swinburne University of Technology, Melbourne, for Telstra. DOI: https://doi.org/10.25916/5f6eb9949c832

- Fear of repercussions stemming from a history of violence and exploitation at the hands of governments, agencies and health providers.

Part of the challenge in providing support for CALD communities is the funding and outcome constraints that limit the capacity of organisations to provide inclusive services. This is experienced across our service streams and includes:

- Outcomes that do not account for the extensive role that familial support systems play in some CALD communities – for example, the key role grandparents and other extended family members play in supporting child and young people, the influence of young and middle-aged adults in family dynamics, and
- Outcomes that do not recognise community diversity and are therefore unable to leverage the strengths of communities, families and individuals

For clients who experience intersecting vulnerabilities, such as clients who identify as CALD with disability, the effects of these exclusions are intensified. Relationships Australia believes that outcomes should be preceded by an explicit articulation of which problems need to be resolved, and acknowledgement of the (sometimes unpredictable) influence of external factors beyond the control of the sector or any elements of the sector. The more complex and multi-factorial the problem, the more intricate its causal relationships. This makes it more necessary to define the problems, and more likely to need genuine and sustained cross-government, sector, disciplinary and services attention.

The numbers of people accessing the NDIS who identify as CALD go some way to quantifying the extent of these barriers. While an estimated 23% of Australians are from CALD backgrounds, only 7% of NDIS participants at the end of 2017 identified as CALD (Settlement Services International, 2019). Services, especially mainstream services, have been shaped by a history of colonisation and imperialism (Dittfield, 2020). While equitable access to services for all Australians is integral to inclusion, social work is a profession based on concepts, problems and solutions which have marginalised and obscured Indigenous knowledge systems (as distinct from modern Western knowledge systems).[11] While significant efforts have been made in recent years to increase cultural competency, there remains a focus on CALD and Indigenous communities as 'the other', groups affected by colonisation and immigration, without an acknowledgement of the development of social work within the context of colonialism and postcolonialism (Dittfield, 2020). More effective cultural competency work would acknowledge the effects and consequences of both and would look to Indigenous knowledge systems for answers to some of the more perplexing challenges facing those who are CALD living with a disability.

We also recognise that the concepts of disability, as well as violence, abuse, neglect and exploitation are culturally-specific. Relationships Australia believes that the Royal Commission has been intrinsic in propelling a national conversation around CALD understandings of these topics, but would like to see further research, investigation and support funded to ensure that these experiences are understood by governments, service providers and practitioners.

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[11] Indigenous here refers to knowledge developed within societies, independent of, and prior to, the advent of the modern scientific knowledge system. I have added a clarification.

Systemic institutionalised neglect and past experiences with trauma at the hands of the system

This ubiquitous experience with structural barriers is part of the systemic institutionalised neglect experienced by those living with disability. The universality of these experiences, and other historical experiences of neglect and exploitation has left this cohort deeply traumatised by the system.

> *The common thread is that all these clients have come to our service feeling there is no space or way through for them in "the system". In their contact with government agencies and community services, they have experienced being labelled, discriminated against, dismissed, unacknowledged, discredited, and disempowered. As a result, these people have developed psychological symptoms such as anger, fear, anxiety, depression, hopelessness, suicidality, etc. Of course, there might have been other life events impacting their mental health, however, their experience of the system has often been central to their current state of distress and suffering.*
>
> \- ***Program manager, Relationships Australia***

The culmination of barriers to service, human rights violations within services and the incumbent loss of autonomy has placed those living with disability in a precarious situation, where the services they need to address their situation are often also the perpetrators of trauma. While providing the counselling and support services for the DRC, Relationships Australia's practitioners note that rather than isolated incidences, many people living with disability have experienced repeating patterns of failures at the hands of institutions, carers and advocates. This is exemplified by:

- Complex enquiries and in-take processes which, due to past traumas with the system, do not eventuate in service provision
- Eroded confidence and trust – establishing a trusting therapeutic relationship between clients and practitioner takes longer than in other services
- The need to educate clients on their rights which have, at times, been violated by previous institutions
- Spending significant time in initial meetings conducting systematic assessments and engaging in coordination and integration of care across Relationships Australia's services, as well as with advocates and other service providers.

The systemic nature of this neglect has been perpetuated by service shortcomings and environmental barriers. Despite best attempts to create an accessible service, when addressing violence, abuse, neglect and exploitation, a lack of reporting mechanisms makes it extremely difficult to address clients' issues in an impactful way. For example:

- The enduring lack of reporting options – in most states and territories, the police are the only option for reporting abuse. For many people living with disability, previous experiences with the police mean this an untenable reporting option, and it is unethical to insist otherwise.
- Lack of alternatives to the legal system – for many living with a disability, the nature of their intersecting vulnerabilities, combined with a lack of support from outside sources, leads

them to continue to rely on their perpetrators as supports. Legal remedies compound (and can exacerbate) long-term issues, rather than resolve them. There needs to be better funding and more options for remedies which ensure the safety and health of ongoing relationships.

- Lack of free, or at least affordable, legal support for representation – when clients do wish to pursue legal remedies, they are confronted with a lack of affordable legal representation. This is particularly the case in rural, regional and remote areas.

Case Study 8:

Elijah*, a young man, presents with suicidal ideation following a series of events affecting his family over the last couple of years. He and his siblings were bullied at school. In one case, it was the teacher who was the bully. Despite reports, the school did not address this. Years later, his youngest sibling was sexually abused at the school. The parents' complaint was poorly handled and largely dismissed by the school and by the school's governing body. This young man is now overcome by the feeling of powerlessness against this injustice. He has lost all hope in the system.

Case Study 9:

Krystal is 26 years old. She has an intellectual disability with the most recent assessments completed at 15 years of age. She was sporadically in the care of her birth mother until formal removal by Child Protection Services in 2006 with long-term Child Protection orders being made in 2008. She was then placed with various foster families until adulthood. Krystal has experienced anxiety and depression as a result.

Although assessed as having a significant delay in most areas of development at 6 years of age, Krystal has successfully pursued her schooling, completed a parenting course, First Aid awareness, and Mandated Notification Training course. She has also obtained a Certificate III in Disability Studies with TAFE in 2014, and is currently enrolled in a Cert II Building and Construction Pathway commencing in July 2021. She receives a Disability Support Pension, but is keen to gain skills that will allow her to work in open employment.

Krystal experienced significant family violence from a sibling that caused her to flee from her home in Whyalla to Adelaide in 2020. She has lived transiently since her arrival in Adelaide, forming a relationship and becoming pregnant with her daughter, born 1st Feb 2021. That relationship broke down within a few months and she formed a new relationship prior to her daughter's birth. Krystal presents as a mildly spoken but confident and determined young woman, whose primary focus is to take all steps possible to be reunited with her children. Her new partner is supportive and willing to co-parent Krystal's children.

Krystal has had four children, all have been removed from her care by Child Protection Services and placed with foster families. Her 4-month-old daughter Lucy*, was taken into foster care a few hours after birth and placed with the birth father. The birth father has had apprehended violence orders made against him, and stated that he plans on moving interstate as soon as the interim orders have expired. The DCP reports demonstrate that they had limited information on Lucy's father but are not seeking a reunification for Krystal and her daughter. Lucy's birth father has two older children who are not in his care.

Case Study 9 continued:

The DCP report cites that the reasons to support removal of Lucy from Krystal's care include;

- Limited engagement from Krystal in DCP processes (Krystal advises that she was not contacted by DCP to attend meetings)
- Non-attendance at contact visits (Krystal advised that there was poor communication from DCP about the visits, for example she did not receive a letter with the details of contact, and was very upset at missing the chance to see Lucy)
- Allegations of drug use (Krystal states she was not asked by DCP to provide blood samples for drug tests, and that she would have been very willing to do so, to show she was not using)
- Krystal's disability – citing evidence about Krystal's intellectual functioning from an assessment that was completed when Krystal was 15. Evidence of Krystal's subsequent education and skills qualifications was not considered. The report states that Krystal requires support with all domains of her life, however she is currently living independently with minimal support and even undertaking tertiary study without support.

Krystal has stated she feels guilty for being taken from her own mother and placed in the foster care system as a young child. She has taken every opportunity to develop her parenting and caring skills, and is proactive in providing the best support possible for her children. Krystal's grief and trauma at having Lucy removed at birth and her parenting skills being discounted due to her disability were such that she chose to self-sterilise rather than risk going through another pregnancy and removal.

Case Study 10:

Harrison* has experienced years of neglect and exploitation at the hands of mental health institutions, but makes remarkable progress in his mental health and well-being with a counselling approach under our service. His experience is validated, and he is heard as a person, beyond the label. From this experience, the client concludes that it was counselling and not medication that he needed all along to heal from past trauma. As part of the exit plan, the counsellor tries to refer this client for further counselling to continue the healing from trauma. However, the experience of referring proves to be complicated. The client's local community health centre refuses the referral for counselling because the client is linked with the public mental health system. They say they cannot provide counselling in such cases. Private psychologists or social workers charge a gap fee that the client cannot afford. Another specialist service providing counselling support to victims of abuse hesitates to take his referral because of his mental health status. The worker feels that this client is being discriminated against because of his mental health status.

In order to achieve sustainable, positive outcomes, a multi-pronged, trauma-informed approach needs to identify root causes and realise long term outcomes for clients and their supports. As such, addressing these issues must be person-centred and not linear, this requires long-term commitment, which is resource intensive and complex.

Working with complexity

In our community of practice meetings, many Relationships Australia practitioners reported that they felt that the establishment of counselling services specific to people living with a disability required them to conceptualise and operate a completely new service, with which both clients and practitioners were unfamiliar. For example, Relationships Australia Victoria has undertaken significant research to establish a Model of Care for therapeutic services requiring case management, to establish best practice. Such a model was not readily available.

Many clients entering our service have never received counselling or therapeutic support. Many found the service as a 'last resort'. Consequently, they have entered our service having lacked support of any kind for some time (if ever), with a myriad of traumas, further complicated by the urgency of other immediate needs such as housing, health care and food. As a result, practitioners have had to shift their practice, focusing on the acute and urgent problems first, through intensive case management, before clients are ready to receive therapeutic support.

> *This is one of the most complex caseloads I have encountered in a service stream. This cohort is the most traumatised group of individuals myself, and my team, have ever worked with, including in DFV. Traditional models of service delivery must be adapted to address this enormous complexity and it can be an exhausting and overwhelming task.*
>
> ***Program manager, Relationships Australia***

Working with complex cases requires practitioners to:

- Understand and assess complex needs – something which is complicated by the past experiences of abuse and trauma, which can lead clients to be reticent
- Manage uncertainty and volatility in clients' needs and expectations – due to the myriad issues facing clients, practitioners report that planning can be difficult due to the ever-changing needs often generated, not by the client's needs, but by deficiencies in other services and supports
- Build and maintain relationships to overcome siloed and fragmented systems – this is complicated by the lack of suitable options to which to refer clients.

Many clients have exhausted all other options available to support them in obtaining immediate needs. If a practitioner is able to locate a service, the (understandable) lack of trust makes it difficult to refer clients. Our service is not funded to provide the complex case-management required and has found that at particular times, for example over the Christmas break, other services reduce their capacity, leading clients to rely on us. These complexities have been compounded during the pandemic and many practitioners report increasing levels of distress among clients.

Our teams have addressed these issues by undertaking reflective practice through:

- monthly community of practice meetings,
- increased supervision,
- attending a variety of training to increase knowledge about the sector and available supports, and
- employing additional supports, such as an Aboriginal peer support community outreach officer, who has connections and lived experience which has been extremely valuable to the team.

Case Study 11 (Jade* from case study 4):

Jade* is able to complete most daily tasks but needs proactive support to assist with motivation to develop skills and build her independence. However, Jade's* experience of funded accommodation has been mostly one of reactive rather than proactive supports. Jade* presents with significant attachment difficulties and personality traits that may result from childhood trauma but are also consistent with a diagnosis of Borderline Personality Disorder. Jade* has difficulty adapting to changes to her routine. She has developed coping behaviours. Staff do not always have the training or experience to understand and respond appropriately. These behaviours include verbal and physical aggression, and learned helplessness. She develops intense and volatile relationships with regular accommodation staff; ultimately, staff burn out and leave. Jade* regularly has to get to know new staff, exacerbating her insecurities and attachment difficulties. Staff view her as 'difficult' and her behaviours as 'attention-seeking'. Jade* has previously made allegations of abuse to police when staff have not acceded to her requests that are outside their support role. For example, to take Jade* home to live with them.

In order to engage effectively with complex systems, our services have addressed complexity in research and evaluation and developed policies across service streams to ensure the entire organisation is adept at addressing these issues. For example:

- After completing awareness training with Maven - a service which works alongside businesses to identify and remove the barriers to accessibility and inclusion - Relationships Australia Northern Territory has taken this opportunity to develop an organisation-wide Disability Access and Inclusion Plan to further embed the work of the DRC service into the structure of the organisation.
- Relationships Australia Victoria funded a significant research project which included a literature review, focus groups and individual interviews to establish a Model of Care for therapeutic services requiring case management, to establish best practice and bring about improvements across many streams of service delivery.

Effectively capitalising on informal support systems

Well-being of clients living with disability

While providing the counselling and support services, as well as other services supporting people with a disability across Relationships Australia, practitioners have noted the significant toll experiences of violence, abuse, neglect and exploitation have on a person's mental health, social connections and well-being. Many report feelings of isolation, loneliness and loss. One of the challenges associated with providing counselling and support for a service stream defined by experiences of violence, abuse, neglect and exploitation, is the effect this maltreatment has on accessing informal support systems. Despite this, establishing informal support systems remains a key aspect of therapeutic work.

Informal support systems are important because they:

- Act as safeguards – protecting an individual's human rights, decision-making, wellbeing and quality of life
- Create social connections which are protective factors against loneliness and mental ill-health
- Can provide advice, support, practical assistance, coaching, advocacy, problem-solving, listening, a reminder, companionship and friendship
- Connection with one informal support leads to other connections

In Heather's* case (Case Study 14, below), the formal support provided by Relationships Australia practitioners enabled her to access informal supports in a variety of different community settings. Despite this, practitioners have noted carers and other supports for people with a disability facing significant challenges when attempting to engage and provide informal supports, especially when dealing with the NDIS, social services and other health services.

Case Study 12:

Heather* is 30 years old, living with an acquired brain injury which was sustained from being run over by a car when she was 15 years old. Heather's* mother was a drug consumer. Heather* discovered her mother and aunt dead in similar and traumatic circumstances. As a result, she suffers from complex grief and she has been in care since the age of 2 years. Heather* started to use drugs by the age of 12 and lost custody of her two young children. Heather* has encountered some issues with the Department of Child Protection (DCP) regarding their assessment of her parenting skills. Although Heather* is aware that she is currently unable to care for her children, the psychological assessment was conducted in a non-disability affirmative manner (giving due consideration to her disability and her cognitive abilities to answer reflective psychological questions). The assessments were also focussed on Heather's* ongoing drug use without consideration of her efforts to develop strategies to move towards a healthy life.

Relationships Australia connected Heather* with an art therapy group as part of our services, which helped with her self-esteem, trust issues, communication and socialisation. Heather* also helped to facilitate the group, with the support of a DRC worker. Support workers have also assisted Heather* with further DSP and NDIS applications and to attend a support group for recovering drug addicts.

Case Study 12 continued:

Heather* was interested in community work, so the practitioner has supported her to facilitate the Relationships Australia DRC Art Therapy group, as well as establish her own support group for people recovering from addictions. Finally, they assisted her to enrol in a Diploma of Community Services. Heather* has also been volunteering with the Salvation Army. The practitioner will continue her mentoring role with this client.

Case Study 13:

Maree* is the mother of Josh*, aged 23 years, who has cognitive, neurological and psychosocial disabilities, as well as physical health issues. Maree came to our counselling service. She is an informal carer who is also struggling with her physical disability and history of trauma. Unable to find the supports her son needed as a child, Josh* dropped out of school and soon became entangled with the justice system. He has been in and out of prison for most of his late teens and early 20's for committing petty crimes. Josh* has developed significant health vulnerabilities including a damaged spleen, in part, due to a lack of support services.

Maree* is worried about her son's precarious health, especially his lack of essential self-care skills (such as regularly showering and brushing teeth). She explains that the services and institutions he has had contact with have never accurately assessed his capacity. Maree* believes that he has no capacity for self-care, proven by the fact that the only time he will access medical care is when he is in a severe health crisis and needs to be taken by an ambulance to the emergency department. He requires ongoing medical treatment, but he is unable to follow up.

She also knows that he will never engage with services of his own accord. This client believes that services should involve her, as she understands and is able to engage with her son. However, she finds that they do not, referring to her son's rights and capacity to make his own decisions.

After each crisis, she ends up being the one carrying the responsibility of looking after him, without any other supports in place. Her life is all consumed by this, and her own needs have become invisible. She expresses having carer's burnout, which she worries could lead to severe depression. She also cannot see a place in the system for her son, and she fears for his life.

Our counselling and support service has provided services for anyone affected by the DRC, including carers, family members, support workers and others. Almost universally, these clients report facing structurally and systemically imposed limitations when attempting to create support systems. While social ties are empirically understood as a key part of the human experience, researchers have also attempted to evaluate social support systems as supporters of health and well-being, finding that they can have a protective role against:

- Becoming a victim or perpetrator of abuse (Huang, Son & Wang 2010; Herrera et. al., 2008)
- Physical ill-health (House, Landis, and Umberson 1988)
- Substance abuse and misuse (Pettersen et. al. 2019)

- Stress and reduced self-esteem (Ozbay et. al., 2007)
- Mental ill-health and poor wellbeing (Productivity Commission 2020)
- Loneliness (Relationships Australia 2018; AIHW 2019)
- Suicidality (Productivity Commission 2020, p.150)

Research on risk and protective factors is rarely definitive. Of course, social support systems cannot guarantee protection from these experiences. Significantly, much of the protective factor research examines individual-level causes, rather than investigating social and environmental factors that lead to these experiences. For people living with disability, those with protective support networks are usually less challenged by other intersecting socioeconomic adversities, making causation difficult to conclude. Yet, through our experience providing services to people affected by the DRC, there are universal experiences of physical, attitudinal, communication and social barriers facing those with disability, that require support systems to respond to. While the individual experience of each client is unique, the need for social connection and support is ubiquitous and irrefutable.

Creating a society in which diversity is supported through respectful and sustainable relationships

A significant proportion of this submission has focussed on the multitudinous challenges facing those living with a disability. It has also delineated how the treatment of diversity has led to extensive experiences of violence, abuse, neglect and exploitation, often by the systems and people put in place to protect these individuals.

While the effects of persistent and pervasive mistreatment at the hands of systems and institutions have been canvassed at length in a number of Royal Commissions and Inquiries,[12] in-depth and contextualised appreciation of the ways in which the disabled community's experiences of violence, abuse, neglect and exploitation intersect with other social issues requires further consideration. In particular, as Australia grapples with the need for system-wide overhaul of the mental health and wellbeing sectors, it is vital that people with disability are included in these plans.

Relationships Australia has consistently advocated on the importance of community-based treatment, care and support in building an Australia that is affirming, inclusive and welcoming of

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[12] For example, Royal Commission into Institutional Responses to Child Sexual Abuse, Royal Commission into Aged Care Quality and Safety, Royal Commission into the Protection and Detention of Children in the Northern Territory, Select Committee on Mental Health and Suicide Prevention, Joint Select Committee on Implementation of the National Redress Scheme, Productivity Commission's Inquiry into Mental Health, Joint Select Committee on Australia's Family Law System, Royal Commission into Victoria's Mental Health System, the interim report by the National Suicide Prevention Officer, the Department of Social Services Consultation on Supporting improvements to the Families and Children activity, Australian Law Reform Commission's Review of the Family Law System, House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into family, domestic and sexual violence, and a variety of recently announced reviews commissioned by the Commonwealth Attorney-General's Department into the operation and effectiveness of elements of Australia's Family Law System.

all kinds of diversity.[13] We believe that the overly-medicalised response to mental health is emblematic of a tunnel-visioned response to other, traditionally medically-understood social diversities, such as disability. The interconnections between, and similarities in, the issues affecting Australia's mental health system and Australia's communities of people living with disabilities must not be ignored. Australia's history of discrimination against, and neglect of these members of our community, and a more recent siloed and fragmented response has led us to a place in which diversity is othered, ostracised and concealed.

Relationships Australia believes that, at the heart of the issues canvassed in these inquires and Royal Commissions, is a lack of recognition of the inherent value of each person and an accompanying inability or indisposition to address the environmental barriers to inclusion. Inclusive societies support people to create respectful and sustainable relationships which constitute the support networks that protect people against mistreatment.

Our practitioners have decades of experience providing social services for groups and individuals facing enormous difficulties. Nevertheless, many of our practitioners working with DRC clients have reported that these clients are more traumatised by their experiences than any other cohort of clients they work with. This is further exemplified by the exhaustion and exasperation of carers, families and other supports who have spent years and lifetimes advocating against the environmental barriers and exclusions faced by people living with disability.

In order to address these structural, institutional and systemic traumas, we require a complete shift in thinking and approach. Despite the *Disability Discrimination Act 1992* (Cth) and the United Nations Convention on the Rights of Persons with Disabilities, ableist attitudes still permeate all aspects of Australian society. Furthermore, while the mistreatment of people with disability is deemed unlawful, accessing these rights depends on using ableist frameworks which fail to recognise the unique needs of those who they claim to protect.

Relationships Australia understands that the solutions to these issues are complex. In a submission advocating so vehemently for the importance of diversity, it would be remiss to suggest that there is a single or unified solution to these issues. However, we will use the final section to outline some broad areas for solution-focussed change based on our, and our clients' experiences.

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[13] See, for example, Submission (13 April 2021) to the Select Committee on Mental Health and Suicide Prevention - Inquiry into Mental Health and Suicide Prevention, Submission (23 January 2020) to the Productivity Commission – Mental Health Draft Report, Submission (7 March 2019) to the ACT Office for Mental Health and Wellbeing – Development of priority areas, Submission (3 April 2019) to the Productivity Commission – The Social and Economic Benefits of Improving Mental Health Issue Paper, as well as other unpublished work.

Key Recommendations

Conceptual solutions

- Acknowledge that ableist attitudes that permeate society, unarticulated or otherwise, are the root cause of violence and abuse against, and neglect and exploitation of, people living with a disability. Without acknowledging, understanding and addressing foundational and persistent ableist attitudes, we risk merely 'plugging the holes', ultimately sabotaging any attempts to improve life for all people living with a disability.
- Acknowledge that much of the violence, abuse, neglect and exploitation experienced by people living with disability is perpetrated by the systems, processes and persons set up to protect people living with a disability.
- Acknowledge that Australia's current bureaucratic systems have little, or no, capacity to accommodate impairments, which should be understood as an *expected* incident of human diversity, and as a result, present as insurmountable barriers for people living with disability to access their human rights.
- Recognise that addressing the myriad of physical, attitudinal, communication and social barriers faced by people with a disability is a continual and resource-intensive process, that is necessary to allow people living with impairments to participate in society on an equal basis with others.

Architectural solutions

- Establish external bodies and frameworks for identifying, disclosing and reporting abuse, violence, neglect and exploitation that are not connected to the institutions that perpetrate these behaviours.
- State and Territory Governments should develop and implement Disability Strategies that ensure the rights of people with disability are protected in their interactions with the education, child protection, family violence and family law systems, justice systems and healthcare institutions.
- Acknowledge the effects of siloed and fragmented systems of care by addressing discrepancies, gaps and obstacles arising from Commonwealth Constitutional power, and its relationships with State powers to legislate, interacting legal frameworks, including child protection and welfare, criminal law, adult guardianship law, mental health etc, interacting accountability and disciplinary mechanisms between the Commonwealth, State and self-regulating professions and difficulties around sharing information between and within governments.
- Resourcing the development and maintenance of an online directory of services to support service navigation for people managing NDIS funding, as well as referral practices for service providers.

- Shifting service funding from focusing on service output to client outcomes. If services are truly outcome focussed, they measure the benefits or changes for individuals or populations, rather than the continued and ill-defined focus on outputs, or at the very best, outcomes targets and indicators.
- Establishing categories within shared data collection systems (such as DeX – established by the Department of Social Services) to capture instances of institutional abuse, systemic discrimination, systemic failures etc, to begin to capture the scale of the issues which affect people with a disability.
- Establish clear communication channels between NDIS planners and the State and Territory Departments of Education, to ensure that the child's care, wellbeing and education is centred and supported.
- Establish a comprehensive cultural competency framework for the Disability Services system, including mainstream services engaged in NDIS provision and other disability services.
- Address the over-reliance on medical diagnoses to receive NDIS funding, provide support for people to obtain diagnoses when necessary, especially in regional and rural locations, and put in place real and substantial supports for people unable to receive NDIS funding.
- Fund research projects which explore how disability is understood and how experiences of violence, abuse, neglect and exploitation are described by diverse cultures, communities and language groups. Integrate these findings and Indigenous knowledge systems into cultural competency frameworks, standards and trainings.

Service solutions

- Fund case management services to assist clients with multiple complex needs navigate service systems.
- Provide continued funding for dedicated, and integrated, counselling services for people living with disability which are:
    - Person-centred
    - Trauma-informed
    - Independent to the NDIS
    - Provided by a variety of mainstream providers, ACOs and integrated providers who have staff with the correct training to avoid further marginalisation
- Provide funding for more flexible service delivery – this could include service provision such as outreach support, drop-in services, telephone and face-to-face counselling.
- Provide genuine and transformative commitment to co-design
- Use co-design practices to continue funding services that have an existing connection with communities to ensure high uptake

- Adopt a multi-layered approach, especially in relation to therapeutic treatment or healing over multiple domains due to the complex trauma often experienced by people living with a disability
- Commit the resources (time, effort, funding) to engage in true co-design for services. This population has historically been under-serviced and excluded from planning and design,
- Acknowledge the breadth and complexity of the population and provide space, time and funding for continued training and creative solutions to achieve and maintain inclusion
- Support providers to create Access and Inclusion Strategies to allow more systemic improvements to accessibility
- Given the prevalence of trauma among this community, fund and promote disability-focussed and trauma-informed training that can be accessed by all allied health practitioners, educators and NDIS contractors
- Shift therapeutic support from asking questions about ‘what is wrong with this client’ to ask ‘what has happened to this client?’

Final Remarks

Thank you for your consideration of this submission. Should you wish to discuss any aspect of it, or the services that Relationships Australia provides, please do not hesitate to contact me by email (ntebbey@relationships.org.au) or our Senior Research and Project Officer, Claire Fisher (cfisher@relationships.org.au), by telephone on 02 6162 9300.

Kind regards

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Relationships Australia

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