

Actively Involving People with Disability

Developing a Disability-Lived Experience Framework for
Canberra Community Law: Project Report

December 2023



Acknowledgements

Acknowledgement of Land

Canberra Community Law acknowledges the Traditional Custodians of the land on which we work in the ACT and surrounding region and recognise any other people or families with connection to the lands of the ACT and region. We pay our respect to the Ngunnawal Elders past, present and future for they hold the stories, traditions, and the cultures of their people.

We are grateful that we share this land and express our sorrow for the costs of this sharing to Australia's First Peoples. We will continue to acknowledge the legacy of our history and strive in our goals to empower our community through social justice.

We hope that our efforts will contribute to a realisation of equity, justice and partnership with Traditional Custodians of this land.

Contributors

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About Canberra Community Law

Canberra Community Law (CCL) is an independent community legal service. We provide flexible and accessible legal services free of charge to people facing financial and other barriers.

Our organisation has been part of the Canberra community for almost 35 years. During this time, we have responded to the changing and increasing legal needs of people in the ACT with trauma-informed and culturally responsive legal services.

We work in collaboration with government, social and legal services both locally and across Australia to realise our vision of a just and empowered community.

We offer innovative programs, communication, education, and systemic advocacy. Our targeted support empowers both clients and the broader community to live a better quality of life.

Our lawyers specialise in legal areas that affect people facing socio-economic barriers to resolving their legal issues. These barriers include insecure accommodation, historical or current experiences of domestic violence or being socially isolated.

Canberra Community Law's Disability Law Service

Our Disability Law service includes Disability Discrimination Law and the Mental Health Justice Clinic. Our Disability Discrimination Law service is the only specialist disability discrimination law service in the ACT. We provide specialist legal services in disability discrimination and related legal areas for people with disability, and associates of people with disability who may have been treated unfavourably because of that association. Our Mental Health Justice Clinic provides socio-economic rights-focused legal services to support people with lived experience of mental ill-health. Whilst working across CCL, our Disability Justice Liaison Officer (DJLO) is based in this team. The role supports both CCL's client and systemic work in advancing access to justice for people with disability.

About this Report

This report describes the methods and findings from Canberra Community Law's project that sought to increase how people with disability informed and shaped our work. CCL benefited from the generosity of lived-experience organisations, peak bodies, community sector organisations, service providers and the government, who shared their knowledge with us. We are sharing this report so that others may benefit from this knowledge and our learnings in this project.

One of the outputs from this project is Canberra Community Law's Disability-Lived Experience Framework on the following pages.

Actively Involving People with Disability

Canberra Community Law's Disability-Lived Experience Framework

This framework describes how Canberra Community Law ('CCL') 'closely consult[s] and actively involve[s]' people with disability. This phrase from the 2008 *Convention on the Rights of Persons with Disabilities* reflects the revolutionary statement adopted by the disability rights movement 'nothing about us, without us'.¹ This state obligation under international law has slowly been translated into federal and territory legislation, policy and practice. Aside from the emerging legal obligations to closely consult and actively involve people with disability in matters affecting them, there are also moral and pragmatic reasons to do so.

CCL has committed to 'lead change towards a just and empowered community through legal services, education, and law reform activities'.² Around two-thirds of people who access CCL services identify as having a disability. Therefore, the active involvement of people with disability is necessary to achieve CCL's mission and values, including social justice and human rights, evidence-based advocacy, empowerment and self-determination, collaboration and engagement.

Language

This framework follows the advice from People with Disability Australia and peak mental health consumer bodies about inclusive language.³ It defines disability broadly and recognises that people identify diversely. This framing of disability is consistent with CCL's Disability Action and Inclusion Plan.⁴ The framework uses the term 'lived experience' to reflect the experiences of people with disability, people who have been or are mental health service consumers, and people with accessibility needs.

1 *Convention on the Rights of Persons with Disabilities*, Opened for Signature 24 January 2007, 2515 UNTS 3 (entered into force 3 May 2008) ('CRPD') Art 4(3).

2 CCL mission. Strategic Plan 2020-2024, <https://canberracommunitylaw.org.au/wp-content/uploads/2021/10/CCL-Strategic-Plan-2020-2024-1.pdf>.

3 See PWDA Language Guide: A guide to language about disability (2021), <https://pwd.org.au/resources/language-guide/> and About mental health consumers (2023) <https://www.vmiac.org.au/info/about-consumers/>.

4 CCL Disability Action and Inclusion Plan, <https://canberracommunitylaw.org.au/about-us/disability-action-and-inclusion-plan/>.

Our Approach

An empowerment model informs CCL's Disability Lived-Experience Framework. People with lived experience are experts on measures that can be taken to improve service accessibility and broader disability inclusion in areas of public life. People with disability have first-hand experience of how human rights violations impact them and adopt innovative measures to reduce harm. To learn from this expertise, CCL, operating within our scope of practice, sustainably and meaningfully engages with disability-lived experience experts.

People with disability are not a homogenous group and have intersecting identities. They face diverse barriers to participating in consultations. Therefore, this framework provides multiple paths to participation. The following describes CCL's approaches to ensure lived experience advice shapes our work.

i. Board Representation

The CCL Board conducts an annual audit of the skills and experience of Board Members. The annual Board audit is designed to identify the skills, strengths, experience, and expertise the current Board members bring to the Board's deliberations. As part of the questionnaire, Board members are asked if they have lived experience of disability. Although the CCL Board does not have identified positions, the annual process is designed to help the Board identify gaps to inform its future recruitment and selection decisions.

ii. Partnerships with Organisations that Centre Lived Experience

CCL partners with organisations that are led by and employ people with lived experience of disability. Examples of this work include CCL's monthly outreach to the ACT Mental Health Consumer Network, CCL and mindDog Australia's community education lunch on assistance animals and your rights, and CCL's *Just Hearing* project with Rebus Theatre on supporting people with mental ill-health in the justice system. These partnerships are opportunities for mutual learning between the organisations.

iii. Listening to Our Clients

CCL has thousands of interactions with community members every year through its legal services. These exchanges enable CCL staff to learn about the legal issue(s) that a person is experiencing and other factors that may interact with their legal issue(s), such as broader health and social needs. CCL staff also benefit from hearing the clients' desired outcomes for discrimination complaint resolution. These outcomes may focus on resolving individual needs or on systemic reform.

iv. Project Advisory Groups (new in 2023-24)

A small advisory group of people with disability will convene to provide advice on CCL's community legal education. Members of this time-limited, closed group will be recruited through an expression of interest process. They will have access to capacity-building opportunities relevant to their advisory role. The group secretariat will work with members to overcome barriers to effective and meaningful participation.

v. Community Roundtables/Workshops/Forums (new in 2023-24)

Recognising that some groups face greater barriers to participation, CCL will undertake closed meetings with communities with disability that face significant barriers to participating in other advisory mechanisms. These meetings may be undertaken in partnership with organisations that have existing relationships with these communities. The meetings will focus on working together to develop measures to meaningfully include these communities in this framework, barriers the community faces to legal services, common legal issues experienced by the community, and identifying priorities for accessible community legal education. In 2023-24, CCL will undertake meetings with Aboriginal and Torres Strait Islander communities with disability and LGBTIQ+ communities with disability.

vi. Technical Advice and Training from Lived Experience Experts (fee-for-service)

CCL accesses lived experience advice from organisations that provide fee-for-service accessibility advice and training. CCL has worked with Scope Australia on the Easy English translation of our Disability Action and Inclusion Plan and sought feedback on the Plan from Next Level Inclusion. CCL also worked with Scope Australia on the Easy English translation of its service brochures and CCL's fact sheet on assistance animals and your rights. CCL staff also undertake professional development designed and delivered by people with lived experience, including through the ACT Deafness Resource Centre, ACT Guide Dogs, Autism Spectrum Australia and Mental Illness Education ACT.

Carers

People who are carers are important in realising the rights of people with disability and play a crucial role in the lives of many people with disability. But, sometimes, carers' needs and rights may conflict with those of people with disability, or their priorities for action may differ. Therefore, for simplicity, the scope of this framework is on lived experience advice from people with disability and people who are or have been mental health service consumers. Nonetheless, some lived experience advisors may choose to bring a support person to enable them to participate effectively in a consultation or advisory group.

The Future

As CCL deliberately and strategically engages with people with lived experience to seek advice, we will learn and subsequently modify this framework. Further, as resources become available, CCL may sustainably extend this framework to other content areas or employ other approaches. Extensions to the framework may include project advisory groups or round tables to respond to law reform inquiries, creating identified (affirmative measures) roles for people with disability (staff, students, volunteers), and engaging people with disability in hard-to-reach places such as prisons and group homes through innovative consultation methods. In the future, CCL may have targeted consultations with people with disability who are young, culturally diverse, women, and older (65+), as well as people with disability living in group homes, people with intellectual disability, people with communication disability, and people with low written and digital literacy and disability.

Measuring Progress

The effectiveness of this framework will be monitored through an implementation plan and annual evaluation meeting described below.

i. Implementation Plan

An implementation plan has been developed to ensure that necessary resources are available to undertake the activities in this framework. The implementation plan will be regularly monitored and updated by CCL's Disability Justice Liaison Officer.

ii. Annual Evaluation Meeting

This framework will be reviewed annually at a meeting that will include CCL's Executive Director/ Principal Solicitor, Disability Law Supervising Solicitor and Disability Justice Liaison Officer. The meeting members will consider reports about framework activities, participant feedback, and the diversity of people participating. The impact of the framework on CCL's practice and outputs and how this may have influenced broader systems will be documented at the meeting. Based on this information and learnings, the group will identify priority communities and approaches for the following 18 months. The framework will be updated to reflect decisions from this meeting, and a brief report will be provided to the board and posted on the CCL website.

For more information about this framework please contact us at info@canberracommunitylaw.org.au or on 02 6218 7900.

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1. Introduction

In its 2022-25 Disability Action and Inclusion Plan ('DAIP'), Canberra Community Law ('CCL') committed to 'investigate the viability of a disability advisory group' to 'ensure that people with disability are included in developing CCL's disability-related strategic processes and initiatives'.⁵ Early project discussions and research indicated that advisory group approaches had limitations. Responding to these early learnings, the project expanded its scope. It evolved to documenting CCL's current approaches to lived-experience advice, considering the gaps and developing a framework with multiple strategies that may increase the diversity of perspectives and the impact of lived-experience advice on CCL's work.

1.1. Project Aims

The project aimed to explore and develop sustainable mechanisms for CCL to include lived experience expertise from diverse people with disability in developing: services and resources, law and policy reform advice and submissions, and other activities that contribute to systemic change for people with disability in the justice system.

1.2. Project Methods

Three methods were employed to gather information and develop the Disability Lived Experience Framework: stakeholder meetings,⁶ reviewing key documents,⁷ and internal steering group workshops.⁸

1.3. Project Governance

The project was overseen by an internal steering group who met at key stages. The group participated in two workshops (described in section 3) and reviewed this final report. The group comprised CCL's Executive Director/Principal Solicitor, Disability Law Supervising Solicitor, Disability Justice Liaison Officer and the Project Worker.

1.4. Project Stages

Figure 1 below illustrates the project stages. While the diagram suggests a linear progression between the project stages, the relationship between the stages was much more iterative. For example, while developing the framework, the steering group identified further information needed to inform the approach. Likewise, the implementation planning helped us refine the framework. As we started disseminating the framework, stakeholder questions helped us refine the framework and the implementation plan. These iterative processes are consistent with CCL's commitment to continual learning. The Disability Lived Experience Framework will be updated as contexts change and we learn more about engaging with the communities with which we work.

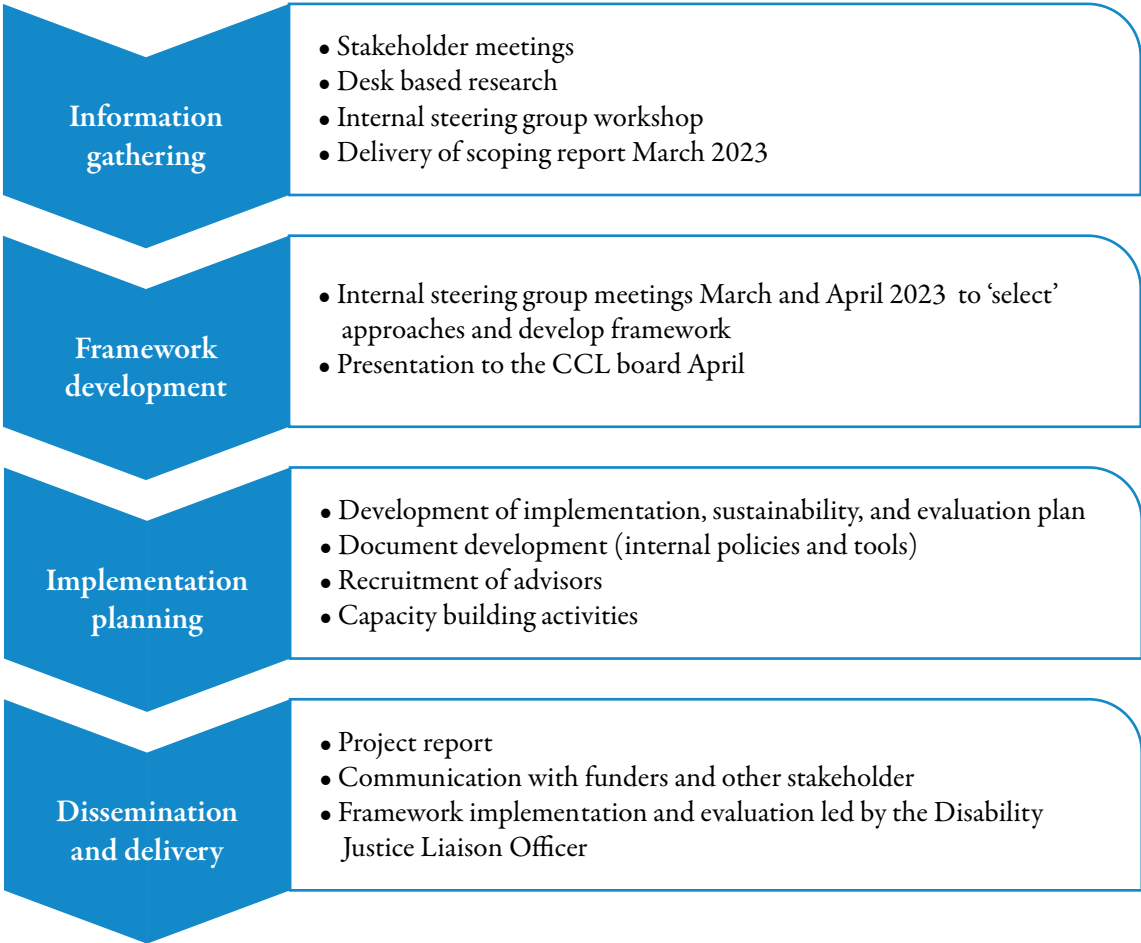
5 See CCL's Disability Action and Inclusion Plan here: <https://canberracommunitylaw.org.au/about-us/disability-action-and-inclusion-plan/>.

6 See appendix 1 for a list of external organisations consulted.

7 See appendix 2 for a list of documents reviewed.

8 This workshop was held on the 10th March 2023 and was attended by the CCL Executive Director, Disability Law Supervising Solicitor, Disability Justice Liaison Officer and the Project worker.

Figure 1. Disability Lived Experience Framework project stages



2. Legal and Policy Context

People with disability have a group right to be closely consulted and actively involved in matters affecting them. This group right is reflected in international, national and territory laws and policies.

2.1. United Nations *Convention on the Rights of Persons with Disabilities*

The widely endorsed 2008 *Convention on the Rights of Persons with Disabilities* (‘CRPD’), an international human rights treaty, was an important milestone for the human rights of people with disability. While Australia has a dualist constitution, meaning obligations in international treaties must be implemented in domestic legislation to make them law in Australia, the CRPD has had a profound impact in many ways.

The CRPD codified the social model of disability.⁹ This model conceptualises disability as a product of unaccommodating social and physical environments. The remedy for disability is, therefore, the removal of barriers to enable effective participation. The CRPD also recognises people with disability as the experts on the human rights abuses they experience. It obligates states to ‘**closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations**’.¹⁰

9 CRPD Art 1.

10 CRPD Art 4(3).

The Committee on the Rights of Persons with Disabilities (CRPD Committee), which monitors the implementation of the *CRPD*, issues authoritative interpretive guidance for the *CRPD*. According to the CRPD Committee, representative organisations, also called Disabled Persons Organisations, are: ‘led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves’.¹¹ The CRPD Committee has also identified the vital role of capacity building for people with disability to undertake advisory roles and recognised the importance of diverse perspectives from people with disability in consultation mechanisms.¹²

2.2. Australia’s Disability Strategy 2021–31

Australia’s Disability Strategy 2021–31 ‘is Australia’s national disability policy framework’.¹³ The Strategy has ‘Outcome Areas’ requiring governments, communities, and businesses to work together to bring about change. One of the seven Outcome Areas is ‘Safety, Rights and Justice’.¹⁴ This outcome area recognises that ‘[p]eople with disability are experts in their own lives’.¹⁵ The strategy’s Engagement Plan outlines the Commonwealth’s approach to engaging with people with disability ‘to inform ... [the strategy’s] implementation, monitoring and reporting, and future direction of policy’.¹⁶ The Engagement Plan contains two methods for people with disability to be actively involved in the strategy. The first method is the Strategy Advisory Council, which contains 11 members, half of whom must be people with disability. The second method is through annual public forums.¹⁷ The Engagement Plan also includes actions about developing resources, such as a website for the strategy materials and a Good Practice Guideline for the Engagement of People with Disability.¹⁸

2.3. ACT Disability Strategy 2023–33

The *ACT Disability Strategy 2023–33* is currently being developed.¹⁹ The Australian Capital Territory (‘ACT’) Government have said that ‘[t]he development of the Strategy will be based on the social model of disability, which ... seeks to change society in order to remove barriers for people with disability; it does not seek to change people with disability to accommodate society’.²⁰ In developing the Strategy, the ACT Government has released a report summarising its community consultations.²¹ The 112-page consultation summary identified that people with disability in the ACT do not have enough input and influence over the policies and decisions that affect their lives.²² This lack of influence over policies and decisions was one of the six reoccurring issues during the comprehensive consultation. The consultation summary stated that ‘[p]eople [with disability] felt excluded from decision-making, and from representation in decision-making bodies’.²³

11 Committee on the Rights of Persons with Disabilities, *General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention*, available [here](#), [11].

12 Ibid see especially [10]-[12], [13], [39], [59]-[60], [94(b),(j)].

13 Commonwealth of Australia, 2021, *Australia’s Disability Strategy 2021-2023*, available here: <https://www.disabilitygateway.gov.au/document/3106>, 4.

14 Ibid 6.

15 Ibid 14.

16 Ibid 45.

17 The Engagement Plan is available here: <https://www.disabilitygateway.gov.au/document/3126>. For more about Australia’s Disability Strategy Advisory Council see: <https://www.disabilitygateway.gov.au/ads/advisory-council>, 1-2.

18 The website is: <https://www.disabilitygateway.gov.au/ads>.

19 <https://yoursayconversations.act.gov.au/act-disability-strategy>.

20 ACT Government, 2022, *ACT Disability Policy – where we’ve been and where we’re going*, 1 (emphasis in original).

21 ACT Government, *Towards a 10-year ACT disability strategy: Listening report 2022*, available here: https://yoursayconversations.act.gov.au/download_file/9744/2240.

22 Ibid 22.

23 Ibid.

2.4. ACT Disability Justice Strategy 2019–2029

The *ACT Disability Justice Strategy 2019–2029* ‘aims to achieve equality and inclusion for people with disability in the justice system’, recognising that ‘equality before the law is not the current reality for too many ACT residents with disability’.²⁴ The plan states that it was developed in collaboration with people with disability who have lived experience of the justice system.²⁵ Importantly, the strategy commits to ‘continu[ing] to listen to people with disability, their carers and families and involve[ing] them at every stage over the lifetime of the Disability Justice Strategy’.²⁶ This strategy funds the Disability Justice Liaison Officer role at CCL.

2.5. ACT Government Disability-Lived Experience Advisory Groups

The **ACT Disability Reference Group** ‘works to ensure the ACT Government is aware of the issues which affect people with disability in the ACT’ and provides advice ‘on ways in which the ACT can be a more inclusive community for people with disability’.²⁷ The reference group comprises people with disability, carers of people with disability and five ex-officio members from government and health services. The majority of the group must be people with disability. The reference group led the consultation process for the ACT Disability Strategy.

The **ACT Mental Health Advisory Council** is established under the *Mental Health Act 2015* to provide advice about emerging or urgent mental health issues, mental health service reforms, mental health policy, mental health legislative change, and anything else concerning mental health and social and emotional wellbeing as requested by the Minister.²⁸ The advisory council may have five to seven members appointed for up to three years, including ‘someone who is or has been a person with a mental disorder or mental illness’.²⁹

The **ACT Disability Justice Strategy Reference Group** works to ‘ensure the lived experience of people with disability is central to the strategy development’, among other things. The membership should include participants with ‘lived experience as a person with disability who interacts with the justice system’.³⁰

24 ACT Government, 2019, *Disability Justice Strategy*, 1.

25 *Disability Justice Strategy*, 5.

26 *Ibid* 20.

27 More about the ACT Disability Reference Group here: https://www.communityservices.act.gov.au/disability_act/disability-reference-group.

28 *Mental Health Act 2015* (ACT), Chapter 14 [239].

29 *Mental Health Act 2015* (ACT), Chapter 14 [240](2)(a-b).

30 https://www.communityservices.act.gov.au/disability_act/disability-justice-reference-group/terms-of-reference.

3. Gap Analysis

Before this project, CCL had several avenues for gaining lived experience advice. These approaches were documented in a workshop with the project steering group in March 2023. Approaches identified included client interaction, partnerships, training, and fee-for-service consultancies with lived experience organisations.³¹ Despite the multiple approaches to gaining lived experience perspectives and advice, steering group members identified areas that needed attention. Discussions from the workshop are summarised below.

3.1. Gaps in CCL's Approach to Lived Experience Advice

The steering group identified the need to embed lived experience advice into the culture and practice of CCL. Embedding lived experience advice requires a strategic, deliberate approach. A reason that this work tends to be more reactive rather than strategic is that resources are required to support consultations. Therefore, consultation occurs when time and money are available, often through grants.

The group also recognised that greater consideration was required of those not currently accessing CCL's services. Work is required to understand why CCL are not seeing these populations and the legal issues they experience.

3.1.1. Areas in which CCL needs lived experience advice

Workshop attendees identified that advice from people with lived experience is important in creating accessible and inclusive services and informing systemic reform.

Advice about accessible and inclusive services may include but is not limited to publications and resources, services and events, environmental accessibility, and inclusive language. Lived experience advice may shape CCL's strategic plan and Disability Action and Inclusion Plan initiatives. It may contribute to grant applications and subsequent initiatives funded by the grants.

Lived experience advice would improve CCL's law reform work and submissions to governments in other consultations, such as the 2022 consultations on the ACT Disability Strategy. The system reform advice may flag emerging needs in the community and inform ACT Government priorities.

3.1.2. From whom should CCL seek advice?

Workshop attendees recognised that CCL needs advice from people with diverse and intersectional experiences of disability. This includes advice from people with disability who are young, First Nations, culturally diverse, LGBTIQ+, women, and older (65+).

CCL also needs advice from people with diverse experiences of disability. CCL should aim to consult with marginalised groups such as people living in group homes, people with intellectual disability, people with communication disability, and people with low written and digital literacy and disability.

Most CCL clients are Centrelink recipients and people living in public housing. Therefore, lived experience advice from those who live in public housing and receive Centrelink payments is important.

³¹ These approaches are described earlier in the Disability-Lived Experience Framework (p.3-4).

3.2. CCL's Capacity to Engage with and Adopt Lived Experience Advice

Workshop attendees identified that CCL's capacity to include people with disability in its work was limited by funding available for resources to undertake this work. The staff member who will lead this work, the Disability Justice Liaison Officer, has limited time and multiple responsibilities. Other resources are available to support this work, such as CCL's Executive Director/Principal Solicitor and the CCL's Disability Law service. CCL has also successfully secured one-off grants to further disability inclusion work. These grants are often important to fund reimbursement and remuneration for lived-experience advisors.³²

Organisational and legal culture is another area that limits CCL's capacity to engage with and adopt lived experience advice. Legal services are places where people come for expert advice on legal matters. Therefore, it is a significant change in mindset to hand power to service recipients and position them as experts providing advice about how services could do things differently. Some of this cultural change is within CCL's power, while some require reform of the broader justice system.

Further, CCL can only respond to lived experience advice within the scope of CCL's vision, areas of expertise and practice. People with lived experience may have interests and priorities outside this scope.

3.2.1. Managing potential conflicts of interest

Professional ethics requires lawyers and legal services to negotiate conflicts of interest carefully. For CCL, managing potential and real conflicts of interest is further compounded by the small size of the ACT jurisdiction, the limited alternative free/community legal services and the specialised nature of the work that CCL undertake. Other sectors, such as health, have been able to navigate the inclusion of past, current and future clients in consultations and advisory groups. Sometimes, being a past or present client is a criterion for participating in health services consultation. Therefore, as we explored ways of including more people with lived experience in the work of CCL, we had to consider how to navigate potential conflicts of interest.

Some scenarios that the steering group discussed included that a conflict may arise when people want to discuss their legal matters as part of the advisory group. Potential conflicts of interest may also arise due to the remuneration and reimbursement offered to those participating in the advisory groups and consultations.³³ As CCL embarks on the journey to include more lived experience advice in its work, it will consciously reflect on removing barriers to participation while maintaining professional ethics. It is impossible to comprehensively describe every situation in which a conflict may arise and strategies to manage these conflicts. Nonetheless, some general strategies to manage conflict of interest may include:

- Ensuring people understand the roles and expectations of advisory group/consultation members.
- Informing people that they are not prevented from accessing services, but the advisory group/consultation is not for legal advice.

³² For more on reimbursement and remuneration see section 6.

³³ Ibid.

4. Stakeholder Consultations

Throughout February and March 2023, the project worker met with ACT disability and mental health peak bodies, Disabled People's Organisations ('DPOs') and service providers to discuss their approaches to lived experience advice in their work.³⁴ Some themes from these conversations are described below.

4.1. About Being an 'Advisor'

Stakeholders told us that **being an advisor is life-changing** for people with disability and people who are mental health consumers. The advisory roles enable people to transition from being passive recipients of 'care' to actively shaping systems and working on behalf of others.

Stakeholders also provided us with **guidance about recruiting advisors**, including the following:

- **Advisors need a level of self-awareness and self-care.** A suggested question for potential advisors was: what do you do to take care of yourself when undertaking this work? Stakeholders acknowledged that while advisors should have a self-care plan, organisations have a responsibility to take measures to keep people safe, including periodically checking in with advisors.
- **Advisors need to have done some work to process their trauma.** People are often ready to be part of advisory groups when they have 'come to terms with things'. Housing and Centrelink issues are emotionally fraught. While accounts of injustices can illuminate a lot, they can also dominate discussions. An advisor's desire to tell an individual story of injustice can hinder strategic conversations. Further, the emotional retelling of traumatic experiences may also be triggering for others with lived experience. Therefore, before people are ready to be advisors, they must have processed some of their trauma.
- **Advisors' ability to provide strategic input.** One stakeholder explained in their experience that individuals representing themselves as opposed to those representing community organisations contribute differently to advisory groups. They observed that the person representing the community organisation often brings strategic, systemic knowledge and skills. Conversely, another stakeholder said they would be careful not to exclude individuals from providing strategic input. They recommended advertising the consultation theme and asking people if they had any relevant experience to inform that discussion.
- **People who are prolific advisors** are passionate, knowledgeable people who sign up for groups and want to make services more accessible. Nonetheless, repeatedly having the same people in advisory forums makes it harder to get diverse opinions. These regular advisors were viewed as both a strength and an issue. Some people have broad knowledge and are skilled at providing advice. However, having the same small group of advisors in many forums enables them to hold a lot of influence and may not make space for new perspectives.
- **Organisations need to consider those who are not engaged.** Consultation/advisory group formats are not going to engage everyone. Therefore, organisations may need to consider various ways to engage with people with lived experience. Organisations representing smaller, more marginalised groups are incredibly busy. Many do not sit on any external committees because they do not have the capacity.
- **Expression of interest processes** should ask applicants to share their stories. They should also ask: Why do you want to be part of this group? Why do you want to contribute? Applicants should be provided with various formats to respond. It is also important to manage people's expectations, e.g. 'Not everyone can be involved'.

³⁴ External stakeholder meetings listed in appendix 1.

4.2. About CCL

Stakeholders also provided us with some guidance about **the preparation that CCL needs to do to incorporate lived experience advice**, including asking:

- **What is CCL's capacity to respond to the advice of people with disability?** Stakeholders told us that an advisory group that CCL will not listen to will not work either. Everyone must be on board with the change, or it will not work.
- **What does CCL hope to achieve by engaging with people with lived experience?** Organisations that identified that they had a 'loose scope' to their advisory groups said they struggled to maintain attendance. People also get consultation fatigue. Recently, there have been consultations about health strategies, disability strategies, inclusive education, and the Your Say website has frequent consultations.

4.3. About Facilitating Effective Participation

Stakeholders provided advice about actions CCL can take to support advisors to participate effectively in advisory groups and other forums. These actions included training and capacity building for advisors and measures to respond to accessibility requirements.

4.3.1. Training and capacity building for advisors

Advisors may attend training and workshops to develop skills to process their personal experiences and consider how those experiences may translate to advice for systemic reform. This process aims to enable people to speak about their experiences safely and with impact. Lived Experience Australia has online training modules, including safe storytelling,³⁵ and MIEACT has developed the DoNoHarm Framework.³⁶ The DoNoHarm Framework is useful for those working with people who want to share their stories and for individuals who want to share their stories. The DoNoHarm workshops cover self-care and boundaries.

4.3.2. Accessibility

Stakeholders also advised that resources for reasonable accommodations and support to participate in advisory groups should be built into organisational budgets or staff members' time. Individuals generally do not have ongoing funding for this type of support.

To enable people to communicate the supports or conditions they require to participate, one stakeholder told us about the Access Rider. The Access Rider is a template that invites people to share some information about themselves and their accessibility requirements.³⁷ This template enables participants to control the information they share and shape how their story is told.

Meeting environments can be stressful. A strategy to promote participation raised by a couple of stakeholders was providing advance notice of the questions to be discussed at an upcoming meeting. Having advance notice of the questions gives advisors time to consider their contribution to the conversation. A stakeholder also recommended offering people with intellectual disability a pre-meeting to support them to write out what they want to say during an advisory group meeting.

35 More about Lived Experience Australia's training opportunities [here](#).

36 <https://mieact.org.au/workshops/do-no-harm-hearing-stories-safely/>.

37 For more on Access Riders see <https://disabilityarts.online/magazine/opinion/access-rider-open-template/> and <https://weareunlimited.org.uk/resource/creating-your-own-access-rider/>.

5. Approaches to Actively Involving People with Disability

The following approaches to including lived experience advice in the work of organisations have been informed by policy documents,³⁸ steering group workshops, and stakeholder interviews.³⁹

5.1. Board Positions for People with Disability

Many organisations that work with people with disability have a minimum number of board positions assigned to people with disability. In some organisations, these roles are supported by a group of people with disability who work with the board member(s) to identify issues and priorities to take to meetings. Like other board positions, people are elected to the lived-experience targeted positions for two to three years. For example, the ACT Down Syndrome Association has two people with intellectual disability on its board.

5.2. Employment of People with Lived Experience (peer workforce)

Organisations may employ people for their lived experience knowledge. Peer workforces require policies, procedures and support networks that are sensitive to the specific issues that arise due to the nature of their work. For example, Woden Community Services has a Mental Health Peer Framework outlining different roles people with lived experience undertake and the support required. Another example is the ACT Down Syndrome Association peer workforce that meets fortnightly to support and provide feedback to each other.

5.3. Co-design

Co-design is a detailed process of designing new initiatives or undertaking major reforms. This approach assumes that considerable change is possible to services and systems. People with lived experience are equal partners with service providers in the process. Co-design, therefore, necessarily involves the transfer of some power to those receiving the services, including decision-making power. Organisations undertaking this method must allow considerable time and engage co-designers at the early conceptual stages of projects. To enable meaningful participation, lived experience advisors may require upskilling outside the co-design meetings. Care must be taken not to co-opt the 'co-design' title without engaging in the rigorous transformative process.⁴⁰

5.4. Advisory Group Meetings

This project identified two types of advisory groups described below: regular and ad hoc.

5.4.1. Regular advisory group meetings

Some organisations have a lived experience advisory group that meets regularly with broad terms of reference. The group may develop a work plan with priorities or structure its work through meeting agendas with items that relate to the group's purpose. Stakeholders reported that facilitating regular advisory groups was resource-intensive. Organisations, therefore, need to make an ongoing commitment of time and resources. Stakeholders also reported low attendance at advisory groups with 'loose scopes'. The strength of regular lived experience advisory groups is that they allow time for developing relationships between the organisation and the advisors.

38 See appendix 2 for the policy documents consulted.

39 See appendix 1 for list of organisations included in the interviews.

40 See Co-design or Faux-design: <https://www.simonkatterlconsulting.com/writing/co-design-or-faux-design-a-chat-with-joszczepanska>.

5.4.2. Ad hoc advisory group meetings

Some organisations convene ad hoc advisory groups for projects and events. The timeframes for these groups vary in length. For example, one organisation had a project over five years, and the advisory group met throughout this time. In contrast, the Mental Health Community Coalition convenes a group yearly to plan Mental Health Week events. The common thread is that these advisory groups meet around a project or event rather than a generalist purpose. In this approach, budgeting for group resources may be tied to the event or project. One difficulty of the ad hoc lived experience advisory group approach is that organisations require a broad network of lived experience advisors to draw on to establish ad hoc groups. Recruitment requires considerable work to build relationships and develop ways of working together - including attending to barriers that may hinder participation. DPOs and other organisations that centre lived experience may assist with recruitment. Nonetheless, recruitment and establishment of advisory groups is time-consuming and needs to be factored into ad hoc advisory group planning.

5.5. Roundtables/Workshops/Forums

Roundtables/workshops/forums are one-off events focused on a theme or objective. Their size varies. Large forums may be good for cross-fertilising ideas. Smaller roundtables/workshops may enable the whole group to work together throughout the entire process.

One stakeholder reflected that roundtables/workshops/forums are less time-consuming for participants and may include a cross-section of people, for instance, the CEO of an organisation and those who access the service. They can be productive spaces to raise ideas and provide individuals and the organisation with a mandate to pursue courses of action. However, the stakeholders also reflected that it was difficult to sustain momentum without a group of people working on the issues raised.

Some stakeholders working for disability service providers said that when a government consultation was released, they asked clients if they would like to provide input on the issue. They would then have a roundtable to workshop ideas with people with lived experience.

Participants may be diverse or comprise a specific community. Closed groups comprising communities with a common identity enable the exploration of experiences unique to that group. For example, Companion House hosted forums with eight different community groups. The groups were differentiated by age, language, gender and sexuality. The project report demonstrated significant variation in the groups' experiences during COVID.

5.6. Aggregating Individual Advice

Stakeholders identified that group approaches to lived experience advice required people to 'automatically disclose' their disability or mental health condition. Giving people an opportunity to provide advice individually allows anonymity. Further, some people are in physical environments that make it difficult to participate in group consultations, such as in prison. Individual visits could be an opportunity to ask detainees if they have experienced any disability-specific issues they wanted to raise that could be included in general feedback.

Aggregating individual advice is also congruent with the current practice of many organisations. For instance, CCL, through its legal practice, has contact with hundreds of clients with disability. CCL staff listen to and act on the instructions of clients regularly. Therefore, CCL staff identify priorities and trends emerging through these interactions. These interactions, stories and learnings may provide insights from people who do not have the time or the capacity to participate in advisory processes, such as people in crisis without stable housing or income.

5.7. Outsourcing

Fee-for-service consultants or organisations can undertake discrete consultations and provide technical advice about accessibility. For example, outsourcing the Easy English translations of documents regularly distributed to clients. Another example is the consultants who facilitate community consultations. Some stakeholders reflected that while outsourcing can be motivated by saving staff time, it can also be time-consuming.

5.8. Partnerships with Lived Experience Organisations, including DPOs

The following approaches assume that lived experience organisations have lines of communication and established trust with the communities they represent. The organisational infrastructure and time to maintain these relationships require resources not always available to lived experience organisations. Therefore, lived experience organisations have varying capacities to undertake the following work.

5.8.1. Joint roundtables/workshops/forums

In this approach, a lived experience organisation creates a safe and accessible environment to co-host roundtables/workshops/forums with service providers. The lived experience organisation may view this joint endeavour as an opportunity to build the service provider's capacity to work effectively with their constituents. Service providers may see this as an opportunity to consult with 'hard to reach' communities. For this approach to be effective, the lived experience organisations and service providers require the same understanding of timeframes and working methods.

5.8.2. Preparing advice for governments

Many organisations work on submissions for the same government reviews. Joint efforts between lived experience agencies and service providers may enable a rich sharing of perspectives that may inform submissions. Coalitions also demonstrate to governments a united front on an issue and may be powerful advocacy tools. Nonetheless, organisations have varying positions on issues and different groups to which they are accountable. Considerable time and negotiations are often required for organisations to reach a shared position. Joint submissions are often not possible due to prohibitive timeframes on government consultations.

6. Reciprocity, Reimbursement and Remuneration

Demonstrating that lived experience advice is valued through a 'thank-you' gift (often gift vouchers), reimbursement of expenses incurred, and/or payment for the advisor's services has become accepted practice. Several resources are available to assist organisations in developing policies and procedures around reciprocity, reimbursement, and remuneration for lived experience advisors.⁴¹

This project's stakeholder consultations also provided insights into approaches to reciprocity, reimbursement, and remuneration for lived experience advisors. There is no standard approach across the ACT regarding the amount of money provided and whether these payments are paid as an employee, a contractor or reimbursement for estimated expenses incurred as a volunteer. Where remuneration was offered, it was generally accepted that community members providing advice as individuals get paid, and staff representing organisations that have funding for advocacy to attend meetings do not get paid.

The sporadic nature of lived experience advisory opportunities was viewed as problematic even when well-remunerated. Advisor payments were often paid as a lump sum and taxed at a higher rate as a second job. Most stakeholders said that people on the Disability Support Pension ('DSP') are concerned about reporting their income and the accrual of a potential debt to Centrelink. One organisation said that people in their peer workforce were concerned that their modest income would 'mess with their DSP'. Another organisation had undertaken impressive work considering remuneration and reimbursement, carefully examining the difference between their peer workforce and volunteers. They told us:

⁴¹ See for example the Guide to Consumer Representative Payment developed by Justice Connect <https://content.nfplaw.org.au/wp-content/uploads/2023/05/Payments-to-consumer-representatives.pdf> or the National Mental Health Commission's Paid Participation Policy <https://www.mentalhealthcommission.gov.au/getmedia/17b27236-8660-48b3-b177-0bbd8c6fcd1/Paid-Participation-Policy-revised-April-2020.pdf>.

The organisation had considered the implications of the Australian Tax Office, Fairwork, and Centrelink requirements. Volunteers receive an honorarium. The organisation's honorarium policy had taken a lot of work to develop, including input from an accountant and lawyer. Honorarium amounts are not linked to hours but to the nature of the task and the likely cost incurred by the volunteer. The organisation recommends that all volunteers gain tax advice about the impact of the honorariums. They found that paying an honorarium gets tricky when the nature of the volunteering is similar to the volunteer's work outside the organisation.

Further, the organisation determined that volunteers cannot do the same work as casual staff. They reported that there have been times when they have said to volunteers that they are sorry that they cannot have them doing certain work because it puts the organisation at risk. The organisation has had people transition from volunteering to casual work, demonstrating the common assumption that volunteering can be a pathway to paid work.

The project's stakeholder meetings and review of documents illuminated the complexity involved in reciprocity, reimbursement, and remuneration of lived experience advisors. To implement the lived experience framework, CCL developed interim guidance on reimbursement and remuneration with the intention of developing an organisation-wide policy to ensure consistency across program areas. Further consideration will also have to be given to the impact of the legal practice contexts, as this differs from the contexts in which the stakeholders interviewed for this project operate.

7. Developing the Framework

Building on the wealth of knowledge gathered through this project's scoping phase, the internal steering group met to develop the CCL Disability-Lived Experience Framework. The project steering group articulated the principles they wanted to inform the framework, including building on existing work, empowerment, collaboration, making sure that people are remunerated, pathways for hard-to-reach voices, meaningful consultation, adequate resourcing (cost, time, people) and flexibility to adapt to new information. The group then developed a framework that could be implemented now and one that CCL could work towards in the future should more resources become available.

Documenting the existing pathways for lived experience advice, reviewing the gaps (section 3), and assessing the available resources, CCL committed to two new approaches. These approaches are roundtables/workshops/forums for less engaged communities and an advisory group (time limited) focusing on community legal education.

After the Disability-Lived Experience Framework was drafted, the project worker presented it to the CCL staff and board. These presentations generated fruitful discussions about measuring the impact of the framework on staff time as well as the language that we adopted to describe meetings with communities. Our Dhurrawang Aboriginal Human Rights Program advised us that the word 'consultation' carried a certain meaning about a broad community-wide consultation not just talking to a few people. As our budget restricted our consultation to about ten people, we changed the language in the framework to roundtables/workshops/forums to demonstrate that language should be tailored to communicate with communities effectively and not build false expectations.

The CCL Disability-Lived Experience Framework will develop and change as we engage with communities and learn more from them. The current iteration of the Framework is in the front pages of this report.

Appendices

Appendix 1: External Stakeholder Consultations

- Lived Experience Australia
- Rebus
- Office for Disability, ACT Government
- Disability Justice Liaison Officer at ACT Courts and Tribunal
- Advocacy for Inclusion
- Mental Health Community Coalition
- Mental Illness Education ACT (MIEACT)
- Companion House
- Woden Community Services
- ACT Down Syndrome Association
- Women with Disabilities ACT
- ACT Disability, Aged and Carer Advocacy Service (ADACAS)
- Health Justice Australia
- Inner Melbourne Community Legal

Appendix 2: Reports and materials reviewed

- ACT Government 'Disability Justice Strategy and First Action Plan 2019-2029'
- ACT Government (2019) 'Towards Disability Justice for the ACT Summary of Research and Consultation'
- ACT Government (2016) 'Consumer, Carer and Community Representative Reimbursement Policy'
- ACT Government (2014) 'Community participation payment policy and claims'
- Commonwealth of Australia (2021) 'Australian Disability Strategy'
- Justice Connect (2022) 'Payments to consumer representatives'
- National Mental Health Commission (2021) 'National Lived Experience (Peer) Workforce Development Guidelines'
- National Mental Health Commission (2020) 'Paid Participation Policy'
- National Mental Health Commission (n.d.) 'Carer and Consumer engagement: a practical guide'
- Victorian Government (2019) 'Mental health lived experience-engagement framework'
- Reports and policies shared in confidence by organisations