

# Engaging lived experience and expertise in domestic violence policy

A research report prepared for Domestic Violence NSW



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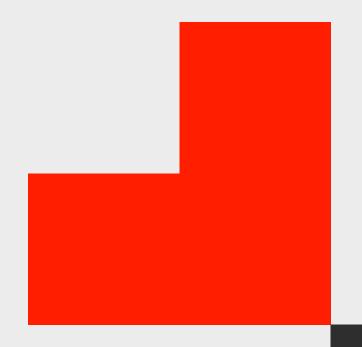
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## Introduction and project overview



#### "No effective solutions can be developed without the people most affected by them...Victim-survivors must be at the heart of solutions."

This opening quote from the National Plan to End Violence Against Women and Children 2022-2032<sup>1</sup> signifies the importance of engaging people with lived experience and expertise in policy design. A growing body of scholarship and public discourse has highlighted the need for people with lived experience and expertise in domestic and family violence (DFV) to be involved in the design and evaluation of DFV legislation, services, policies and programs.<sup>2</sup> However, sharing lived experience as part of engagement processes can be stressful and potentially (re)-traumatising whereby a thought, activity, or situation may trigger a stress response in a victim.3 Engagement frameworks and guiding principles are essential so that professionals can effectively and safely engage people with lived experience.

Domestic violence is prevalent in Australia and remains a widespread human rights abuse and public health problem. Domestic violence is also a gendered phenomenon, with women experiencing higher rates of DFV compared to men, commonly by male perpetrators, as well as facing gendered types of violence.4 There are also unique complexities around gender and violence in LGBTQIA+ communities, which contribute to under-reporting in some cases.5 While commonly portrayed as a 'private' matter, Weatherall<sup>6</sup> draws attention to the fact that "domestic violence is a multifaceted problem that plays out socially as well as individually, at home, in the law courts, in hospital, and...in the workplace."

While there is no single definition of DFV, Domestic Violence NSW7 describes it as: "when someone behaves abusively towards a person they are in an intimate or family relationship with. Domestic and family violence is part of a pattern of behaviour that controls or dominates a person and makes them fear for their own and/or other people's safety and wellbeing." Abuse can manifest in different ways, be it financial, verbal, emotional, spiritual, psychological, physical or sexual. While DFV can be experienced by anyone regardless of their age, gender, race, sexual orientation or other characteristics, rates of DFV are more prevalent among certain populations, including people with disability, Aboriginal and Torres Strait Islander people, LGBTIQA+ people, and those living in rural, regional or remote locations, due in part to the higher levels of discrimination experienced by these groups.8

Commonwealth of Australia, 2022, p. 68

e.g. Backhouse et al., 2021; Blomkamp, 2018; Doyle, 2021;

Backhouse et al., 2021; Department of Families, Fairness and Housing, 2022, p. 9; Lamb et al., 2020

<sup>4.</sup> Australian Institute of Health and Welfare, 2023

<sup>5.</sup> ACON, 2018

<sup>6.</sup> Weatherall, 2022, p. 430

<sup>7.</sup> Domestic Violence NSW, 2022, p. 87

<sup>8.</sup> See Our Watch 2021 n.d. for a summary

Co-design can be a way to bring about change. Co-design is a method for enabling those affected by a particular policy problem to be involved in finding solutions. A key principle of co-design is that people with lived experience in an issue should be centred in the policymaking process and that policy outcomes are informed by those with lived experience. This process should also be carried out alongside other forms of knowledge, including empirical evidence, practice expertise and advocacy<sup>10</sup>, recognising that one form of knowledge does not necessarily privilege another.

A growing evidence base has documented the benefits of incorporating the voices of those with lived experience in policy design (including DFV policy design), such as that the needs of serviceusers will be better met, and those sharing their experiences may feel more empowered and derive meaning from sharing their stories.11 Indeed, it has been recognised in the National Plan to End Violence Against Women and Children 2022-2032 that "[t]o achieve [the goal of ending violence against women and children in one generation], we must listen to and be guided by victimsurvivors and people with lived experience".12 Similarly, the 2021 National Summit on Women's Safety called on the next National Plan to embed formal mechanisms where those with lived expertise would have input into governance, policy implementation, monitoring, and evaluation.





<sup>10.</sup> See Safe and Equal, 2022)

<sup>11.</sup> Blomkamp, 2018; Howlett and Migone, 2013; Lamb et al., 2020; Royal Commission into Family Violence, 2016

<sup>12.</sup> Commonwealth of Australia, 2022, p. 18

However, there are concerns that, to date, there has been a lack of meaningful and comprehensive engagement of individuals with lived experience in policy design.<sup>13</sup> Moreover, it is often overlooked that engaging lived experience and expertise in policy design is complex: there are significant ethical and safety concerns; system-wide frameworks are lacking to guide engagement between policymakers and those with lived expertise (be it one-off or ongoing); there is a knowledge gap in the ways people with lived experience may be engaged in the co-design process; and research in this area is lacking and diffuse, with mixed evidence on the benefits from lived experience engagement. In Australia, gaps particularly remain in the context of New South Wales, with acknowledgement that further systems work is needed to formally engage those with lived experience of DFV as part of policy processes. For example, while an outcome of the Victorian Royal Commission into Family Violence (2016) was the introduction of a funded Victim Survivor's Advisory Council to Government that consults those with lived experience in the family violence reform program, no such formal equivalent body exists in New South Wales at the Government level. Further, while some frontline DFV services and peak organisations have processes to collate and integrate lived expertise into practice and policy work, this is constrained by a lack of funding for lived expertise consultation and co-design.

To advance this goal, this report presents a literature review of lived experience engagement and ideates a draft framework for engaging people with lived experience of DFV. The question guiding this report is: What is an effective model for engaging people with lived experience and expertise in the development of DFV policy? In consultation with Domestic Violence NSW, a literature review was undertaken to understand the value of engaging lived experience, and develop draft guidelines informed by extant literature. As part of this goal, it is recognised that competency frameworks and engagement models need to be suitably priced to reflect the expertise of people with lived experience and which also provide wraparound safety and support.

#### What is an effective model for engaging people with lived experience and expertise in the development of DFV policy?

## 02. Method

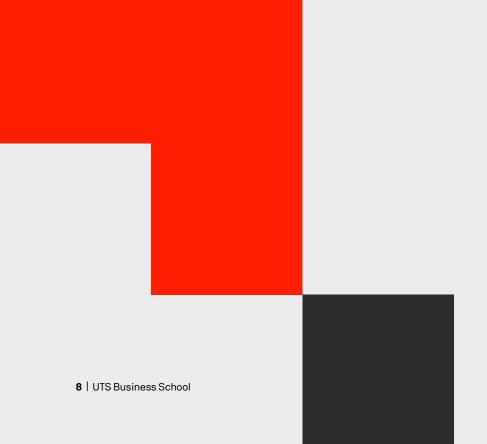


A primary research question and supporting questions were arrived at in consultation with Domestic Violence NSW to inform the literature review and development of a draft lived experience engagement framework. A literature review was conducted via a search of academic research as well as publicly available grey literature (practitioner and NGO reports, government reports, media articles, websites of specialist DV organisations) relevant to answering these questions, carried out with support of a Research Assistant. Literature searches were undertaken focused on lived experience of DFV and in other areas, where relevant, such as mental health.

Search terms included combinations of the words: \*advocate\*, \*best practice\*, \*co-design\*, \*domestic violence\*, \*family\*, \*framework\*, \*harm\*, \*lived experience\*, \*lived expertise\*, \*mental health\*, \*model\*, \*outcomes\*, \*paid\*, \*participation\*, \*policy\*, \*policy-making\*, \*principles\*, \*professional development\*, \*remuneration\*, \*safety\*, \*stigma\*, \*survivor\*, \*trauma\*, \*victim\*. The review exercise particularly focused on locating articles, reports, guidelines or practice notes that incorporated frameworks for engaging lived experience. There was no restriction to the publication date of published documents in the searches undertaken. In addition, the reference lists from research articles were hand-searched for further potential sources. The research questions guided the reading and thematic analysis of the documents.



## Defining lived experience and expertise



Lived experience as a concept and practice can be understood in various ways.14 Quite often this term is used with little clarification of its meaning or enactment in practice.<sup>15</sup> According to Sandhu,<sup>16</sup> 'lived experience' may be understood as the experience of people on whom a social justice issue has a direct impact or where a person has "direct, personal experience of a particular issue or service". 17 'Lived expertise' may be understood as the knowledge, insights and understanding that is gained through lived experience.<sup>18</sup> NCOSS<sup>19</sup> distinguishes between 'context expertise', that which people with lived experience possess, compared to 'content expertise', which may involve having a paid job or qualification related to DFV, engaging in research on DFV as a researcher/academic, or expertise acquired through DFV service provision.20

Having convincing evidence is important for influencing policy, practice and services.21 Unfortunately, as noted by Robinson, 22 what 'counts' as evidence can sometimes be narrowly defined. A growing body of literature recognises people with lived experience as "experts in their own experiences"23 or 'experts by experience'.24 Lived experience can be considered a type of expertise and thus challenges typical notions of privileged, expert knowledge in advisory settings.<sup>25</sup> Durose and Richardson<sup>26</sup> note that conceptualising lived expertise in this way does not mean that scientific evidence or professional expertise is lost, diluted or ignored in policymaking processes. Rather, lived experience provides a value-add to formal evidence through contextual information, local knowledge and experience.

Commentary in this area acknowledges perspectives which state that (lived) experience is highly individual or unique to a person, which may limit generalisable accounts. However, lived experience can still provide a very reliable and informative source of contextual knowledge. As emphasised by Scott: What could be truer... than a subject's own account of what he or she has lived through? Wheildon et al. Similarly note that "one form of knowledge should not be privileged above another, reinforcing how "[v]ictim-survivors are experts in their own lived experiences and... they are likely to have valuable insights to contribute to the development of policies and services."

Insights from lived experience can provide a window into 'shared typical' experiences of victim-survivors, providing common narratives and shared intersubjective experiences.<sup>31</sup> This is also backed-up by the scholarship on Evidence-Making Interventions which aims to debunk 'conventional hierarchies' of expertise and objectivity, and acknowledges the value of lived experience and expertise alongside scientific knowledge.<sup>32</sup>

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<sup>14.</sup> Werner-Seidler and Shaw, 2019

<sup>15.</sup> McIntosh and Wright, 2019

<sup>16.</sup> Sandhu 2017

<sup>17.</sup> CFE Research, 2020, p. 6

<sup>18.</sup> Sandhu, 2017

<sup>19.</sup> NCOSS, 2021, p. 9

<sup>20.</sup> Safe and Equal, 2022

<sup>21.</sup> CFE Research 2020, p. 11

<sup>22.</sup> Robinson, 2021

<sup>23.</sup> Cabinet Office 2017 cited in Blomkamp, 2018; see also Department of Families, Fairness and Housing 2022, p. 24

<sup>24.</sup> CFE Research 2020, p. 6; Lamb et al., 2020

<sup>25.</sup> Ailwood et al., 2022; Howlett and Migone, 2013; CFE Research, 2020, p. 11

<sup>26.</sup> Durose and Richardson, 2016, p. 41 cited in Blomkamp, 2018

<sup>27.</sup> See McIntosh and Wright, 2019

<sup>28.</sup> McIntosh and Wright, 2019

<sup>29.</sup> Scott, 1992, p. 24 cited in McIntosh and Wright, 2019

<sup>30.</sup> Wheildon et al. 2022, p. 1703

<sup>31.</sup> McIntosh and Wright, 2019

<sup>32.</sup> Rhodes and Lancaster, 2019

# Engaging lived experience: rationale and outcomes

Policy design can commonly involve diverse individuals, including citizens, stakeholder groups, experts and professionals.33 There is a growing discourse that policy across areas not limited to DFV, health care, criminal justice and drug use, should be informed by the people it directly affects.34

#### Centering lived experience in policy co-design

Engaging people with lived experience in policy design can help to identify gaps in response systems and services, and ensure the voices of victim-survivors inform policy development and service delivery.35 Indeed, it is considered 'good policy' that which is informed by people whom it most directly affects,<sup>36</sup> and also facilitates social inclusion and participation.37 Put quite simply by Lancaster et al.,38 "[p]olicy should be informed by the people it directly affects." Unfortunately, many systems have failed to listen to, believe and act on the stories and experiences of those facing violence (predominantly women) which, in turn, can fuel reluctance to engage in a system which has failed them. Such a gendered lens is also crucial given the gendered profile (predominantly male) of policymakers.

Since the 1980s in Australia, it has become more common for the expertise and knowledge of 'service users' to be drawn upon by policymakers.39 While there have been important developments in incorporating lived experience in health, disability and mental health sectors in Australia, 40 progress in the area of DFV has been slower, with voices of victims often missing or subordinated to privilege certain (other) 'kinds' of knowledge. Moreover, genuine engagement requires a change in the culture and operation of government agencies as well as devolution of power and decision-making.41

A key message from the Royal Commission into Family Violence (2016) was the importance of embedding lived experience of victim-survivors in all aspects of the family violence system including responses. As noted in the report summary and recommendations, "[p]olicy makers and others responsible for the design, responsiveness and efficacy of the family violence system should hear directly from victims who have recent experience of the system so that improvements can be made".42 Others have similarly noted that "[e]xperts [with lived experience] provide a powerful and authentic voice and unique insights that can challenge assumptions, motivate organisations to do things differently and pinpoint areas for change".43 Put simply by Hague and Mullender,44 engaging with lived experience "is not an optional extra".

<sup>34.</sup> Dovle et al., 2021: Lancaster et al., 2013: Werner-Seidler and Shaw, 2019

<sup>35.</sup> Champions of Change, 2021; Skelton-Wilson et al., 2021; Safe and Equal, 2022, p. 5

<sup>36.</sup> Doyle et al., 2021

<sup>37.</sup> Holmes, 2011; Lancaster et al., 2013; Robinson, 2021

<sup>38.</sup> Lancaster et al., 2013, p. 60

<sup>39.</sup> Ailwood et al., 2022; De'Ath et al., 2018; Walklate et al., 2019

<sup>40.</sup> De'Ath et al., 2018: Robinson et al., 2021

<sup>41.</sup> Ailwood et al., 2022; Holmes, 2011

<sup>42.</sup> Royal Commission into Family Violence, 2016, p. 8

<sup>43.</sup> CFE Research 2020, p. 3

<sup>44.</sup> Hague and Mullender, 2006, p. 585

#### Benefits from lived experience engagement

According to researchers, practitioners, advisory groups and service providers, among others,45 there are key benefits from lived experience engagement, which include:

- Research outcomes and processes are strengthened
- Trust and cooperation between diverse groups is enhanced
- Solutions to complex real-world problems may be found which are more efficient, effective and safe, and relevant to local needs
- More diverse and detailed perspectives which help to contextualise issues
- Policymakers gain greater insights into challenges and experiences of those most affected by policy decisions and how decisions impact people's lives
- Improved policies, services and programs so that they meet the needs of users
- Reflects 'good governance' that can enhance trust and legitimacy and promotes social inclusion
- Brings awareness to issues of safety and confidentiality in DFV policy and service design, thereby ensuring responses are safe and inclusive
- May help to challenge negative stereotypes, discriminatory attitudes or stigmatising perspectives

Individual benefits may also flow to those people who are sharing their lived experience. As argued by Mission Australia,46 those who have overcome life adversities are "uniquely placed to role model, mentor, and sometimes challenge people in their own overcoming processes".47 Discussing stories of overcoming adversity may also provide victimsurvivors with an opportunity to 'reclaim' or even construct a new identity and show that healing is possible.48 Victim-survivors may gain greater confidence and self-esteem, feelings of pride and empowerment in being able to contribute to change, personal development, as well as greater access to support, connection to community, and employability opportunities.<sup>49</sup> Writing in the context of mental health, others also identify that such involvement can lead individuals to live a meaningful and contributing life.50

#### Co-design and its impact

While terms such as 'co-design' and 'coproduction' are increasingly common in government discourse, a clear and shared definition is lacking.51 Notwithstanding this, Blomkamp<sup>52</sup> provides a guiding definition of 'co-design' as a method whereby people who are affected by a particular policy problem (service users) are active participants in the process and design of making decisions and finding solutions. It reflects democratic conceptions of enhancing participation and empowerment by those impacted by policy decisions. 'Co-production' involves citizen engagement where the focus is on joint action.53 Services can be created, delivered and evaluated jointly by people with lived experience who use those services.54 'Co-design' may be a form of co-production involving policy development and service planning. The notion of 'engagement' refers to strategies to include citizens in the policymaking process, in this case, where individuals with lived experience influence and shape policy decisions and outcomes.<sup>55</sup>

<sup>45.</sup> e.g. Backhouse et al. 2021; Black Dog Institute 2020; Blomkamp 2018; Champions of Change 2021; CFE Research 2020; De Ath et al. 2018; Doyle et al. 2021; Hague and Mullender 2006; Howlett and Migone, 2013; Lamb et al., 2020; Lancaster et al. 2013; Safe and Equal, 2022; Sandhu 2017; Werner-Seidler and Shaw 2019

<sup>46.</sup> Mission Australia, 2018

<sup>47.</sup> Mission Australia, 2018, p. 5.

<sup>48.</sup> Heywood et al. 2019 cited in Bancroft, 2021

<sup>49.</sup> CFE Research, 2020, p. 3; Sandhu, 2017; Skelton-Wilson et al., 2021; Suomi et al., 2020; Werner-Seidler and Shaw, 2019

<sup>50.</sup> Black Dog Institute, 2020; Werner-Seidler and Shaw, 2019

<sup>51.</sup> De'Ath et al., 2018

<sup>52.</sup> Blomkamp, 2018, p. 731

<sup>53.</sup> Loeffler and Martin, 2015

<sup>54.</sup> CFE Research, 2020, p. 6

<sup>55.</sup> Skelton-Wilson et al., 2021

There is some empirical evidence, albeit limited and varied, which attempts to evaluate the impact of co-designed policy. Weaver and McCulloch<sup>56</sup> note limited research existing which examines relationships between service user participation in service/policy development and improved outcomes. Writing in the US context, Skelton-Wilson et al.57 note how limited research exists which captures the impact of lived experience engagement for shaping outcomes of federal programs and initiatives. An Australian study on the criminal justice system found that programs for inmates informed by the experiences of reformed individuals who had spent time in prison were effective.<sup>58</sup> Miller et al.'s<sup>59</sup> study on problem gambling also found benefits when the experiences of people with problem-gambling behaviour were drawn upon, including policies that focused on reducing harm. While there are anecdotal claims of the impact of lived experience provision for improving service outcomes,60 others<sup>61</sup> observe a lack of empirical research or rigorous evaluation for claims of benefits arising for policymakers or end-users. Further research is needed to strengthen understandings of codesign for policy in practice and its impact for end-users.62

Consequences of ineffective engagement

Risks and consequences arise when policy design and implementation fail to consider impacts on end-users, when those with lived experience are poorly engaged in these processes, or when engagement produces other negative outcomes. Ailwood et al.63 argue that a key reason why DFV has persisted despite years of campaigning and advocacy is the absence of law reformers and policymakers actively 'listening' to the voices of those impacted by violence. Moreover, the mechanisms by which women's voices are

incorporated into policy recommendations or law reform are often obscured from public view.64 Genuine engagement can be constrained due to bureaucratic processes and ambitious timelines for policy implementation.65 Backhouse et al.,66 writing on advocates' experiences engaging with media and in events with external stakeholders, note how advocates felt not taken seriously by policymakers and government representatives, and experienced reinforcement of negative assumptions.

This can result in services and systems that produce negative outcomes for victims, such as lack of access to key resources to help rebuild lives, as well as practices of 'victim blaming', and people with lived experience feeling unheard, marginalised or disempowered.<sup>67</sup> Victim-survivors can be left feeling vulnerable and distrustful of systems if first responders are dismissive, and 'secondary victimisation' can manifest when victims are forced to continually retell their stories when engaging with systems and service providers.<sup>68</sup> Wilcox<sup>69</sup> and Liang<sup>70</sup> describe this as a 'maze' through which victims must negotiate in order to find pathways to safety and recovery.

56. Weaver and McCulloch, 2012 cited in De'Ath et al. 2018

57. Skelton-Wilson et al., 2021

58. Seppings, 2015 cited in Dovle et al., 2021

59. Miller et al.'s 2018 cited in Doyle et al., 2021

60. Asad and Chreim, 2016: Loeffler and Boyaird, 2016

61. e.g. Blomkamp, 2018; Voorberg et al. 2015 cited in Blomkamp, 2018

62. Blomkamp, 2018

63. Ailwood et al. 2022

64. Ailwood et al., 2022

65. Wheildon et al., 2022, p. 1697.

66. Backhouse et al. 2021

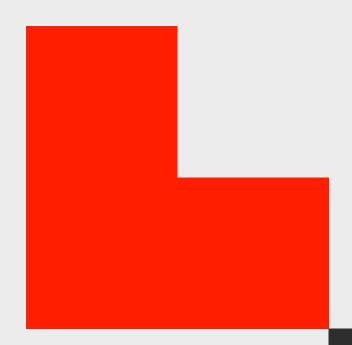
67. Kelly et al. 2014; Suomi et al. 2020

68. Liang, 2013; Moulds, 2022; Wilcox, 2010

69. Wilcox 2010

70. Liang 2013

## Sources of lived experience and engagement



There are different sources of lived experience and thus diverse ways in which those with lived experience can participate to enact change. Safe + Equal<sup>71</sup> set out three ways in which lived experience can be embedded within the family violence sector: lived experience in the workforce - those individuals who work directly in the sector (e.g. practitioners, advisors) who may also hold lived experience and may choose to disclose this (or not), lived experience of clients – or 'client voice' which describes input into activities based on client knowledge and experience to enhance service delivery, and lived experience of survivoradvocates - where those with lived experience use their experience to influence policy development, service design and delivery, and system reform.

More about these sources of lived experience in the DFV sector, its diversity, and complexities to note are explored further in the Safe + Equal report.<sup>72</sup> Importantly,73 draw attention to these sources of lived experience not being mutually exclusive and rejects privileging one form of knowledge as more legitimate or valuable than another; rather, system responses need to be informed by multiple forms of knowledge, including empirical evidence, practice expertise and lived experience. Safe and Equal74 also observe the power imbalance that may exist across these sources, which can reflect the power imbalance in violent relationships. Safe and Equal therefore emphasise the importance of taking a 'power with' approach when co-producing policy in an effort to strike a more even redistribution of power and decision-making.

There are various reasons why those with lived experience may choose to engage in policy and service design which affects them, the forums and settings in which this can take place, and the level of engagement involved. It is important that engagement takes place when victim-survivors want to be engaged in lived experience work, and when support is available to facilitate this. 75 It is also important to recognise the diversity of lived experiences that exist, and the need to ensure representation of this diversity in engagement.

#### Forms of engagement

There is no one-size-fits-all for the nature and extent of lived experience engagement. De'Ath et al.76 note that 'participation' is very broadly defined and exists on a spectrum that varies from consultation on one end, to setting agendas for policy change in the middle, and developing resources on the other end of the spectrum. Robinson<sup>77</sup> argues that, in practice, mechanisms for participation are actually fairly narrow. Werner-Seidler and Shaw<sup>78</sup> observe that engagement occurs along a 'continuum' from relatively low engagement, to where work is initiated or led by those with lived experience. A different form of engagement may be required for different projects or activities, which each hold value. However, in whichever process, it is crucial that engagement is meaningful and not tokenistic or reduced to a 'box-ticking' exercise.79 As argued by Hague and Mullender,80 "user participation needs to be carried out in a deeply human and meaningful way and not just as an administrative mechanism."

<sup>71.</sup> Safe + Equal, 2022, p. 5

<sup>72.</sup> Safe + Equal report, 2022

<sup>73.</sup> Safe and Equal, 2022

<sup>74.</sup> Safe and Equal, 2022, p. 5, p. 12

<sup>75.</sup> Moulds, 2022

<sup>76</sup> De'Athet al 2018

<sup>78.</sup> Werner-Seidler and Shaw, 2019

<sup>79.</sup> CFE Research, 2020, p. 3; Sandhu, 2017 p. 32; Wheildon et al., 2022, p. 1697

<sup>80.</sup> Hague and Mullender, 2006, p. 585

Lived experience input that requires less-intensive engagement may include information-sharing, advice, consultation, participating in interviews, surveys or focus groups for research, acting as consultants for research or as part of project reference groups, media engagement, involvement in community campaigns and activist projects, and participation in events or speaking engagements. This can be distinguished from more-intensive engagement which include involvement in participatory action research or co-design of projects, advisory groups to government or NGOs, positions on governance boards, steering committees, or leading organisational strategic planning.81 For instance, those with lived expertise may provide input into matters but may not necessarily lead initiatives, whereas co-designed engagement sees experts have greater leadership and a stronger voice in steering initiatives.

The type of activity can therefore influence the nature and extent of lived experience engagement. For instance, a speaking invitation may be limited to a one-off engagement, whereas evaluation aimed at improving practice may involve several engagement activities.<sup>82</sup>

An area gaining attention is embedding lived experience expertise in governance arrangements, particularly at national levels of Australian social policy. Various victim-survivor advisory and advocacy groups currently exist in Australia which hold expert knowledge that is valuable for informing DFV policy development, prevention activities and system reform.83 For instance, the Victorian Victim Survivors' Advisory Council was formed in 2016 comprising members with lived experience who provide input into family violence policy development and reform. Taking another example, on the issue of modern slavery, the NSW Anti-Slavery Commissioner's Advisory Panel also includes representation of survivor-advocates. The National Plan to End Violence Against Women and Children 2022-2032 recognises the importance and value of such groups in playing an active role in contributing to policy development and implementation and the need for ongoing engagement and consultation to support policy implementation.84

In discussing lived experience engagement, it is worth noting the challenges that exist for policymakers as part of the engagement process. Holmes<sup>85</sup> notes that questions abound of exactly 'who' should participate in such processes, being aware of risks that may exist in this process and capabilities needed to manage these, power imbalances that exist between policymakers and people with lived experience, and challenges in capturing diversity of lived experience across diverse groups (including different cultural sensitivities) and categories of difference within these groupings.86 As mentioned, hierarchies of knowledge can shape what evidence 'counts' which may influence 'who' gets to speak.87 In summary, the range and diversity of those with lived experience is vast; it is important that voices are representative, while also acknowledging that a single voice does not represent all stories or perspectives.

Backhouse et al., 2021; Hague and Mullender, 2006; Lamb et al., 2020; Lancaster et al., 2013; Skelton-Wilson et al., 2021; Werner-Seidler and Shaw, 2019

<sup>82.</sup> Skelton-Wilson et al., 2021, p. 10

<sup>83.</sup> Backhouse et al., 2021

<sup>84.</sup> Commonwealth of Australia, 2022, p. 68

<sup>85.</sup> Holmes, 2011

<sup>86.</sup> Ailwood et al. 2022; Hague and Mullender 2006

<sup>87.</sup> Hammock 2019 cited in Robinson, 2011

Policymakers should also be sensitive to the ways in which engaging the 'ideal victim' can potentially (mi)shape policy design. In drawing on a case study of anti-violence campaigner Rosie Batty, Wheildon et al.88 caution that, although 'ideal victims' play a crucial role in advocating for system-wide change, they may not necessarily be representative of all victims, particularly those from diverse and marginalised communities.89 Policymakers should be aware of this to ensure that policies are designed which are representative of, and responsive to, a wide range of voices and experiences.90 This all highlights that while a goal of co-design is to improve policies and services, engaging lived experience in this process is not a panacea. How government and other DFV services listen and respond to victimsurvivors is an area needing further attention and investigation.91

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<sup>88.</sup> Wheildon et al., 2022

<sup>89.</sup> Walklate et al., 2019; Wheildon et al., 2022

<sup>90.</sup> Wheildon et al., 2022

<sup>91.</sup> Wheildon et al., 2022, p. 1702

# Value, recognition, remuneration and resourcing



"We need to ask ourselves why service providers are funded and supported while engaging in such activities, whereas abused women are expected to participate in their spare time and out of kindness, goodwill, or personal commitment."

As well as elevating the role and value of lived experience in policy design, frameworks are also essential which recognise the skill and effort of lived experience engagement, acknowledge participants in outcomes, and ensure engagement activities are appropriately remunerated. Consultation of victim-survivors undertaken to inform the development and implementation of the National Plan to End Violence Against Women and Children made this clear:92 the expertise of victim-survivor advocacy roles should be valued and appropriately remunerated for time and commitment akin to other professional contributions, that recognition of expertise is crucial, and investment in professional development for victim-survivors is necessary to support meaningful participation in the policy design process.

Backhouse et al.93 reinforce this, highlighting that the skill, knowledge and professionalism of lived experience advocates is crucial to "challenge the ways people with lived experiences of domestic, family and sexual violence are stigmatised, patronised and demoted to tokenistic forms of representation." Mission Australia<sup>94</sup> similarly emphasises the skills and competency associated with lived experience and expertise work: "Being able to provide professional lived expertise supports demands a demonstrated competency much more than the simple identification of the experience of adversity alone [...] The uniqueness underpinning all of these ways of working is deeply rooted in the personal and collective knowledge, skills, and principles gained from overcoming the impacts of adversity..."

Many argue that provision of lived experience should be remunerated, and appropriately so.95 Hague and Mullender96 highlight an "uncomfortable situation" that can exist when those impacted by violence engage in unpaid labour to improve system-wide issues: "We need to ask ourselves why service providers are funded and supported while engaging in such activities, whereas abused women are expected to participate in their spare time and out of kindness, goodwill, or personal commitment." Such remuneration may include compensation for time, expenses such as travel to a venue and/or child care, and interpretation or translation services for those whose first language isn't English.97 Such financial support is imperative, as Hague and Mullender<sup>98</sup> plainly argue, "successful participation is something that cannot be done on the cheap."

Arguments supporting paid participation include that lived experience provision can impose a time cost on those participating in engagement activities; people with lived experience have unique knowledge and skills; the fact that advocates in the past have typically not been paid for their participation; and that it supports victimsurvivors' financial security and independence.99 It is also important that remuneration isn't simply tokenistic or insufficient e.g. lunch, or shopping vouchers. Ideally, lived experts should be offered professional development, mentoring and training.

<sup>92.</sup> Fitz-Gibbon et al., 2022

<sup>93.</sup> Backhouse et al., 2021, p. 80

<sup>94.</sup> Mission Australia, 2018, p. 4

<sup>95.</sup> e.g. Fitz-Gibbon et al., 2022; Lamb et al., 2020; Sandhu, 2017

<sup>96.</sup> Hague and Mullender, 2006, p. 579

<sup>97.</sup> Hague and Mullender, 2006

<sup>98.</sup> Hague and Mullender, 2006, p. 580

<sup>99.</sup> See Aizer, 2010; Showalter, 2016

Several existing frameworks provide guidance on remuneration and paid participation, commonly drawn from the mental health sector. In the Australian Government National Mental Health Commission's<sup>100</sup> paid participation policy, those eligible for participation payments include people with lived experience of a mental health condition who may or may not access mental health services and supports, family members or friends providing support, or unpaid support people or carers who provide daily care. However, it excludes professional consumer/care consultants (those engaged to provide professional services through government tenders or are contracted to supply services for the Commission).

The Black Dog Institute's 101 policy on paid participation outlines that payment is provided where the Institute is seeking particular advice informed by lived experience in order to further their work, the person does not hold an existing formal role with the Institute, and is not being funded by other groups to represent the Institute in other engagements. The policy sets out that payment may vary based on the role and activity performed, paid on a daily or hourly basis, and include compensation for travel.102 The policy outlines that the Institute will provide clear guidance upfront about the nature of the activity, expected time commitment and duration, and expected outcomes. Activities attracting payment may include acting as a member of an advisory panel, chairing a committee, participating in meetings or workshops, or speaking engagements. Activities which don't attract payment include (not limited to) attendance at social events, ad hoc communication, or contracted professional consultant work.103 Participation rates are derived from the Australian Government Tribunal Remuneration and Allowances for Holders of Part Time Public Office Determination, as "Offices not specified".



100. Australian Government National Mental Health Commission's, 2019

101. Black Dog Institute's, 2020

102. Black Dog Institute 2020, p. 6

103. Black Dog Institute, 2020

The Family Violence Experts by Experience Framework sets out a tiered remuneration model based on the level of engagement. For instance, co-production activities (e.g. positions on boards) may attract a sitting fee, hourly rate or salary rate based on the duration of the activity. Consulting activities (e.g. participating in a focus group) would attract an hourly rate. Similarly, the NSW Council of Social Service sets out a 'per hour' rate depending on the activity and level of involvement. Activities attracting payment include where an advocate is an active participant, advisor or consultant.

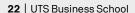
Further work is needed to explore the ways in which skill, expert knowledge and professionalism of victim-survivors can be acknowledged, recognised, valued and appropriately remunerated, and to understand appropriate methods for setting and revising pay.<sup>106</sup> Currently this work in the DFV sector is piecemeal and often relies on short-term, targeted funding and resources to sustainably engage and support victim-survivor expertise.107 It is also important to acknowledge the financial cost of effectively engaging people with lived experience and other resource requirements. Funding models in the DFV sector, whether it be research, policy or frontline service provision, must incorporate adequate funding to remunerate, engage and adequately support lived experts in line with best practice guidelines. In New South Wales, no single organisation is currently exclusively funded to carry out or manage lived experience 'work'. Such activities are typically carried out from existing funding and resources of these organisations (e.g. not-for-profits), which may be limited. Consideration should therefore be given to designing funding models that enable appropriate remuneration for lived experience engagement as well as allow organisations to coordinate training and development activities and support the safety and wellbeing of lived experts (e.g. de-briefing, developing appropriate safety plans for victim-survivors).

Currently this work in the DFV sector is piecemeal and often relies on short-term, targeted funding and resources to sustainably engage and support victim-survivor expertise.

<sup>106.</sup> Backhouse et al., 2021

<sup>107.</sup> Backhouse et al., 2021; Fitz-Gibbon et al., 2022

# Supporting and safeguarding lived experience engagement



In addition to valuing and remuneration for lived experience engagement, greater attention needs to be paid to the development and provision of psychological support, safety and wellbeing services for engagement activities, confidentiality/anonymity, as well as investment in professional development so that victim-survivors may meaningfully participate in policymaking processes.108

It is important that lived experience provision is grounded in safety and security. 109 Wilcox 110 notes that experiencing 'secondary victimisation' through poor engagement safeguards is not uncommon. Victim-blaming, not being believed by system responders or having their stories de-legitimised, as well as services that are not trauma-informed, can result in poor experiences and outcomes for victim-survivors. 111 Such system practices again mirror the de-legitimising that victims of violence can experience when seeking support. Furthermore, consultations with people with lived experience often happen in groups (or focus groups) and secondary trauma may be created from hearing other people's stories (not just recounting one's own).

Psychological support and services for victimsurvivors involved in engagement activities may include (not limited to): risk assessment and safety planning, support persons, capacity to make anonymous contributions to protect identity, post-activity debriefing and counselling, and improved consultation processes.<sup>112</sup> Professional development and training for victim-survivors is also key to help them act as effective representatives and enable meaningful participation. 113 This supports capacity-building and can help increase the confidence and knowledge of victim-survivors. 114 For example, the Voices for Change program which focused on provision of media training for survivor-advocates placed a focus on content knowledge of domestic violence and sexual assault, skill development for media engagement, and self-care techniques.<sup>115</sup> Training should also extend to government, media, and other service providers to understand safe and trauma-informed processes for engagement.<sup>116</sup>

Part of this support strategy is also recognising that victim-survivors have diverse lived experiences, with different experiences of violence and trauma, and intersecting complexities.117 Thus, training should be inclusive of diverse voices and experiences, accessible to all groups, and emphasise emotional and cultural safety for diverse groups<sup>118</sup> also highlight the fact that through the course of their engagement activities, victim-survivors may receive disclosures from others who have experienced violence, thus safe engagement is crucial.

<sup>108.</sup> Fitz-Gibbon et al., 2022; Hague and Mullender, 2006; Safe and Equal, 2022

<sup>109.</sup> Wilcox, 2010

<sup>110.</sup> Wilcox, 2010

<sup>111.</sup> See Fitz-Gibbon et al., 2022

<sup>112.</sup> Backhouse et al., 2021; Champions of Change, 2021; Safe and Equal, 2022, p. 10

<sup>113.</sup> Fitz-Gibbon et al., 2022; Hague and Mullender, 2006

<sup>114</sup> Backhouse et al. 2021

<sup>115.</sup> Backhouse et al., 2021

<sup>116.</sup> Backhouse et al., 2021

<sup>117.</sup> Backhouse et al. 2021; Commonwealth of Australia 2022, p. 63

<sup>118.</sup> Backhouse et al., 2021. Safe and Equal, 2022, p. 11

# Summary of guiding principles for lived experience engagement



It is acknowledged that within the DFV sector, models for, and the practice of, engaging lived experience are emergent and developing, particularly in New South Wales. As much knowledge in the sector is informal, guidelines may exist but perhaps are not 'codified' in written or documented form. The draft guiding principles summarised in this report were informed through various sources: desk-based research which included a review of publicly available frameworks, guidelines, guiding principles and reports for lived experience engagement in the DFV sector (and other sectors where relevant); evidence and best practice insights derived from the literature review undertaken; as well as extensive consultation, input and review from Domestic Violence NSW staff. The draft guidelines at points reflect areas of commonality across existing frameworks at a broad level, where appropriate (see Appendix 1) and as informed by extant literature and academic research, however are not representative or reflective of any single source. Thus, it remains a work-in-progress and should be read in conjunction with other guiding principles and frameworks which have also involved direct consultation with lived experience groups. 119

#### **Draft guiding principles**

#### 1. Prioritising victim-survivor and traumainformed engagement

Policymaking processes actively prioritise the value of lived experience engagement, alongside research, practice knowledge and other forms of expertise, and take a traumainformed lens to engagement.

#### 2. Safety, care and wellbeing

Safety and wellbeing is prioritised for victimsurvivors to ensure safe, effective engagement.

#### 3. Whole-of-experience engagement and support

Victim-survivors feel prepared and supported to participate in an engagement activity. Support is provided before, during and following engagement activities. Participants are remunerated for time and costs.

#### 4. Robust policy engagement processes

Engagement processes encourage diversity of representation, match participant experience to engagement opportunities, understand and seek to mitigate power imbalances that exist, and strive for ongoing, sustainable engagement.

#### 5. Systems are gender-informed and expertise led

Engagement processes and policy design consider the gendered nature of domestic and family violence, as well as advance system reform to address systemic failures.

#### 6. Accountability, transparency and evaluation

There is follow-up to show the impact and outcomes of victim-survivor participant involvement. Lived experience participants are acknowledged for their participation, and embedded feedback-loops provide information on how their input will be used.

#### 200 1. Prioritising victim-survivor and trauma-informed engagement

#### Victim-survivor centred

- People with lived experience are considered to be experts in their own experience, and are valuable and vital in policy analysis and development
- Opportunities are provided for those with lived experience to have their voice heard and listened to
- Engagement is carried out in a way that is sensitive and authentic

#### Trauma-informed engagement

- Recognise that trauma is usually associated with the experience of DFV
- Engagement is guided by a traumainformed lens focused on principles of safety, trust, choice, collaboration and empowerment<sup>120</sup>

#### **Practice examples**

- Policy processes incorporate the voices of lived experts in a variety of different ways, from planning, identifying key priorities, to research, and developing policy positions
- Efforts are made to understand trauma and its impact on victimsurvivors through trauma-informed practice
- Lived experts are provided with choices regarding how they provide their input, e.g. in face-to-face meetings, virtual meetings or in writing
- Coordinators of lived experience groups build trust through consistent communication and provision of information, respectful attitudes and behaviours



120. See Blue Knot Foundation, 2020



#### Safety, care and wellbeing

#### Safety and wellbeing

- Safety in various forms is essential: physical, mental, emotional, social, cultural and psychological
- Recognise that people need to be at a certain part of their journey to participate
- Identify risks that may compromise safety due to engagement in policy work (e.g. identity revealed, lack of confidentiality)
- Recognise that recounting experiences can be re-traumatising. Lived experts may be able to identify in advance the topics or issues that are likely to be a trigger, but unexpected reactions may occur. Equally, those engaging lived experts shouldn't assume that retraumatisation will occur and should avoid infantilising victim-survivors
- Prioritise cultural safety by committing to self-determination for Aboriginal and Torres Strait Islander people

#### **Prioritising** self-care

- Recognise burnout is possible from direct lived experience engagement as well as hearing others' lived experience stories
- Understand one's own boundaries
- Plan to mitigate risks of secondary trauma at both structural and individual levels

- Take steps to mitigate risks e.g., providing option for anonymity
- Provide debriefing and support with skilled counsellors
- Create informal spaces for mutual or peer support and communitybuilding amongst lived-experts
- Engage participants when they feel safe and comfortable to contribute; for some people this may be after certain milestones are complete such as the finalisation of court processes
- Provide information about and encourage healthy coping strategies for self-care and dealing with triggers
- Provide information about referral pathways and support to access referrals when needed
- Encourage early identification of signs of stress or re-traumatisation and encourage help-seeking
- Frame help-seeking as a strength rather than a sign of weakness
- Promote the voices of marginalised communities
- Advocate for and promote Aboriginal-led initiatives and policy work
- Ensure representation of Aboriginal and Torres Strait Islander people on advisory committees
- Provide workers with training on vicarious trauma and clinical supervision
- Create a culture that recognises signs of vicarious trauma and encourages help-seeking
- Maintain a reasonable workload and ensure that exposure to potentially traumatising content is balanced with other, less triggering, work
- Offer training on vicarious trauma as well as supervision during group consultations



#### 3. Whole-of-experience engagement and support

## Prior to activity

#### Induction and setting expectations

- Ensure there is a briefing about the activity prior to engagement to ensure lived experts feel prepared and ensure quality consultation
- Outline roles, responsibilities and expectations of engagement
- Information about the policy environment and context is provided

#### Training and professional development

- Provide training in systems change and transferable skills to support understanding of the policy development environment and enhance skill development
- Build awareness of how people with lived experience can contribute to systems change, and enable experts to represent the collective interests of others

#### Accessibility, language, and support

**During activity** 

- Enhance accessibility of the engagement process, use appropriate language, and provide support

- Brief participants prior to engagement e.g., clarify agenda, purpose, attendees, time commitment, degree of influence, and level of participation
- Participants are offered relevant training prior to engagement e.g., communication, presentation skills, media engagement, policy writing, advocacy, or political processes
- Seek feedback from lived experts on the efficacy of training and make improvements where required
- Offer mentoring or coaching where applicable and resources allow
- Check whether any accessibility supports are required in advance, e.g. disability access, mobility aids, translator, large print, regular breaks, etc.121
- Use language and communication that is plain and understandable, culturally sensitive, nonjudgemental, empathetic, and respectful
- Provide appropriate support structures, contact persons, and regular check-ins
- Accommodate individual accessibility needs e.g. inclusion action plan122

<sup>121.</sup> See People with Disability Australia, n.d.

<sup>122.</sup> See People with Disability Australia, 2021



#### 4. Robust policy engagement processes

#### Diversity and intersectionality

- Recognise that no one victimsurvivor represents all experiences
- Ensure there is flexibility on who sits on committees, forums etc (rather than only 'fixed' people/positions), to provide diversity

#### Match experience to opportunity

- Align participant knowledge and experience to specific engagement activities to allow for meaningful contributions

#### **Understand power** dynamics and imbalance

- Understand that there is a power differential between victimsurvivors and policymakers; power imbalances may mirror that of the power imbalance in abusive relationships and there is a risk of misuse of power
- Consider and deploy strategies to reduce this power imbalance to reach equity

#### Ongoing engagement

- While various engagement activities may necessitate different levels of participation, recognise that engagement should be an ongoing, purposeful activity and not tokenistic
- Consider ways in which lived experience can be embedded into systems and structures to ensure sustainability, rather than relying only on individuals
- Ensure enough time is built in to enable people with lived experience to be involved at all stages, including generating reform priorities and ideas, planning and project mapping, implementation and evaluation. Demonstrate a sustained commitment to embedding lived experience into policy development, persevering despite any challenges that arise, and investing the necessary time and resources that are required

- Strive for diversity and representativeness of participants in terms of type and recency of lived experience and intersectional identity including linguistic and cultural background, age, socioeconomic background, sexuality
- Ensure voices of marginalised groups are included such as people with disability and LGBTIQA+ people
- Ensure representation of metro as well as regional and rural areas
- Take a 'power with' approach that enables those with lived experience to contribute and compensates for time and costs123
- Expand opportunities for participation (e.g. via lived experience groups) rather than relying only on individuals
- Provide lived experts with opportunities to chair meetings, inform agenda items and attend meetings with key decision makers
- Consider ways to include lived experience in governance structures, evaluative mechanisms, and strategic planning processes
- Resist the temptation to give up when challenges arise
- Be willing to sit with discomfort that may arise during robust conversations



#### 5. Systems are gender-informed and expertise led

### Understanding complexities of domestic violence

- Policymaking processes need to be gender-informed not gender-blind
- Build awareness and knowledge of the complexity of domestic violence, its gendered drivers and impacts, as well as the role of power and control

#### **Practice examples**

 Acknowledge that DFV is gendered, but is also experienced by LGBTQIA+ people and men

#### Expertise led system design

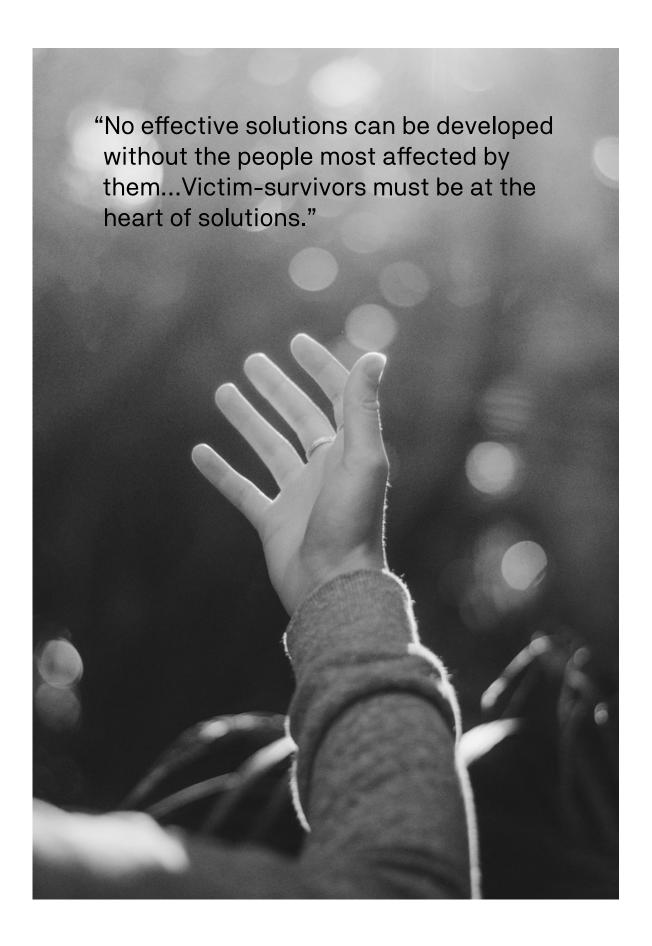
- Enable engagement of lived experience to shape system reform and redress systemic failures
- Be willing to acknowledge mistakes and pivot where necessary

#### 6. Accountability, transparency and evaluation

Embed accountability, transparency and evaluation in policy processes

- Ensure accountability and transparency is built into the policymaking and consultation process when engaging lived experience
- Embed evaluation into lived expertise engagement, to identify what worked well and opportunities for improvement

- Inform participants of the impact and outcomes of reform processes
- Develop and share policies, procedures and terms of reference for lived expertise input
- Provide safe opportunities for feedback to be provided, including the option for anonymity



## Conclusions and next steps



The draft principles form part of ongoing work to develop a robust framework for engaging lived experience in DFV policymaking and reform. The findings from the literature review support the need for a specific framework around engaging lived experience and expertise in policy design and development. Further consultation, workshopping, and evaluation of the framework is required, with victim-survivors of diverse lived experiences and from diverse community and cultural backgrounds, as well as advocates, service organisations, and policymakers, to ensure it meets the needs of stakeholders and to enhance its utility and effectiveness in policy environments.<sup>124</sup> Other resources may also be created to ensure effective

engagement, to support enactment in practice. There is ongoing scholarly work needed to also empirically document and evaluate the benefits and impact of lived experience engagement in policy contexts, as well as understand risks and challenges that may arise. In addition, an area often overlooked is engaging children and young people who are victims of violence and have lived experience.<sup>125</sup> Further work is needed in elevating the voices of young people, designing safeguards and practices which are sensitive and appropriate to their needs, and ensuring early intervention and system responses are appropriately tailored.<sup>126</sup>



124. e.g. see Lamb et al., 2020 125. Fitz-Gibbon et al., 2023 126. See Fitz-Gibbon et al., 2023

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