"Real lives, real jobs"



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Developing good practice guidelines for a sustainable consumer workforce in the mental health sector, through participatory research.

Principal researcher: Wanda Bennetts

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“Real lives, real jobs”

Developing good practice guidelines for a sustainable consumer workforce in the mental health sector through participatory research

Final Report

### May 2009

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Julie Anderson, Isabell Collins, Vrinda Edan, Ellie Fossey, Jo Green, Margaret Grigg, Ben Isley, David Mithen, Lei Ning, Greg Oke, Allan Pinches, Noel Renouf, Cath Roper.

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# Executive Summary

### Purpose of study

* This study was conducted to gain a better understanding of the consumer workforce; the issues facing consumer workers in relation to recruitment and retention; and the contribution of consumer perspective work in mental health services.
* It aimed to identify recommendations for systematic planning, support and career development of the consumer workforce in the mental health sector to ensure the growth and sustainability of this workforce.

### Literature review

* Policy guidelines at national and local levels support the development of a robust consumer workforce, however recent reports indicate the need for a renewed commitment to consumer workforce development in practice.
* Consumer workforce growth over the past decade has not been matched by proportionate increases in funding, resources and infrastructure support. Additionally, attention to the consumer workforce and its activities has been notably lacking.
* The major issues facing the consumer workforce include infrastructure and resources to support equitable and suitable working conditions; limited availability of education and training; attitudinal barriers related to issues of power and the value placed on consumer contributions; and the impact of these factors on the personal safety of consumer workers. Taken together, these issues challenge the effectiveness of consumer perspective work, and the opportunities for advancement, development and long-term sustainability of the consumer workforce within the mental health sector.

### Study method

* This study explored consumer workforce issues in the mental health sector, through consumer-led participatory research guided by a project reference group comprising members of the consumer workforce and members with nursing, occupational therapy, social work and psychiatric disability, rehabilitation and support sector backgrounds.
* Information gathered was through focus groups and interviews with twenty-four consumer workers about their experiences in the consumer workforce, and analysed thematically.

### Key findings

* The essence of consumer work: Consumer perspective work was an enriching and challenging experience, which enabled individuals to contribute to a broader movement and cause.
* The dollars: Remuneration and pay levels for consumer perspective work did not adequately reflect the reality of workers’ lives, the demands of the job, nor the work conditions available to the wider mental health sector. Funding and involvement in budgetary decision-making was also limited.
* Pathways: Education, training, peer supervision and support opportunities for consumer perspective workers are underdeveloped and often unavailable. There

was contention about the content, academic orientation and implementation of education and training for this workforce. However, it was agreed that education and training is needed, and should be consumer-designed and led to reflect the values and approaches underpinning consumer perspective work.

* The workplace: A supportive environment was identified as critical to the success of consumer work, however participants reported attitudinal, resource and infrastructure barriers that hindered consumer activities. This impacted on both the personal safety of individuals and the effectiveness of consumer workers.
* Leadership: The need for leadership from within the consumer workforce and from the mental health sector, more broadly, was identified by participants as critical to promoting the status and value of consumer work.

### Key recommendations

* Address the issues regarding job infrastructure (including options for full-time and part-time employment, adequate pay levels, wage parity and sufficient equivalent full-time positions), both to reflect the size and demographics of each service, and to enable consumer perspective work to be conducted efficiently and effectively.
* Expand consumer workforce roles in education and training for the mental health workforce through staff training in area mental health services, psychiatric disability rehabilitation and support services, and within university education courses.
* Enable equitable funding and access to ongoing professional development for all consumer workers, including Consumer Advisory Groups and casual consumer workers, to address individuals’ needs and build workforce capacity, as well as foster consumer leadership. In particular, professional development designed and delivered by consumer workers should be supported.
* Ensure the availability of formal and informal support, including supervision and mentoring, to promote personal safety and professional development of consumer workers, and foster job satisfaction and retention.
* Match consumer workforce expansion with resources, support and funding to foster the emergence of diverse and far-reaching consumer worker roles on all levels of the mental health sector.
* Support the establishment and separate funding of Consumer Advisory Groups as integral to consumer perspective work in mental health services, and building the capacity of the emerging consumer workforce.

# Introduction

The consumer workforce is a widely recognised part of Victoria’s mental health workforce (Department of Human Services, 2002). In 1996, people with direct experience of mental health issues were first employed in Victoria’s public mental health services as Consumer/Staff Collaboration Consultants, now commonly shortened to consumer consultants. Their introduction was intended as a mechanism to enhance the quality of mental health services through dialogue between service providers and consumer consultants, and to improve the responsiveness of services to the needs of consumers (Wadsworth & Epstein, 2001).

Over the past decade, consumer worker roles have rapidly expanded to include participation in service evaluation, education, advocacy and research activities. There are also ever-increasing expectations that consumer consultants and other consumer workers have input into major areas of mental health service delivery, as well as increasing demand for input into university programs across the health care disciplines. At the same time, the organisational structures and supports for development of the consumer workforce in the mental health sector have not kept pace with this expansion, and a range of challenges and difficulties have emerged.

The attitudes and responses of other mental health staff to the introduction of consumer consultant positions, and to working with consumer workers have varied considerably (McCann et al., 2006; Middleton et al., 2004; Pinches, 2004). Consumer workforce development is further hampered by limited financial and material resources, remuneration and time allocated to these roles; their low status within mental health service organisations; and stress associated with working in unclear roles with often multiple and competing demands (McCann et al., 2006; Middleton et al., 2004; Pinches, 2004). These issues in turn contribute to difficulties with recruitment and retention of consumer workers, and a lack of career development opportunities necessary to ensure the sustainability of this part of the mental health workforce.

Little work has been undertaken to examine consumer workforce issues in a systematic way, as a report by New Zealand’s Mental Health Commission (2005) noted: *“The lack of attention given to the service user workforce developed over the past decade has resulted in a small, underdeveloped and neglected arm of the MH workforce” (p.9).*

This study sought to explore the consumer perspective work being undertaken by the consumer workforce in Victoria’s mental health sector, so as to better understand the issues facing consumer workers employed in mental health services, and to inform the further planning, support, training and career development of the consumer workforce in Victoria’s mental health sector. In addition, the study was intentionally designed as consumer-led research to support the building of research capacity within the consumer workforce in the mental health sector.

## Research questions

* What are the current range of roles being undertaken by consumer workers, and the skills and knowledge necessary to fulfil these roles?
* What are the current gaps in workforce training, mentoring, supervision and other supports for the consumer workforce in mental health services?
* What resources and supports are necessary for consumer workers to undertake their roles in mental health services effectively?

To address these questions, key themes in current literature on consumer workforce issues were identified, and focus groups and interviews with consumer workers in Victoria’s mental health sector were conducted. The scope of this study was restricted to consumer workers. Neither the issues faced by other types of health care workers employed in the mental health sector, who may experience mental health issues were explored, nor those of people experiencing mental health issues who are employed in other workforces, albeit that both topics are worthy of research in their own right.

Notes about language

Consumer worker

People in consumer participation related roles are variously referred to as ‘consumer advocates’, ‘consumer representatives’, ‘consumer workers’, ‘consumer consultants’, and the ‘service user workforce’. For the purpose of this report, the term ‘consumer worker’ is used, and refers to people with direct experience of mental health services in the consumer workforce (CWF) in roles that promote consumer participation as an imperative in itself. So, it includes consumer consultants employed in Victoria’s area mental health services and those undertaking consumer perspective work elsewhere in the mental health sector, whether paid or unpaid.

Consumer perspective work

Consumer perspective is multilayered: all consumers are expert on their own personal experiences of mental health issues and services, and have something relevant to contribute drawing on this firsthand, or lived experience. Additionally, consumers may also have expertise in what may be termed the ‘consumer body of knowledge’ (Wadsworth & Epstein, 2001), this being wider knowledge of the kinds of experiences and everyday life issues that consumers face, their current and historical situation collectively, as well as the nature of the service systems and discourses that affect consumers (Epstein & Olsen, 1998; Sozomenou et al, 2000). Consumer workers draw on this multilayered body of knowledge in undertaking consumer perspective work.

# Literature Review

## A brief overview of consumer participation

The Victorian Government’s Department of Health and Community Services (1996) defined consumer participation as:

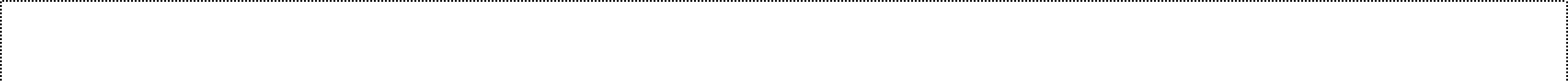
*“…a process to improve the quality of service delivery and increase the level of consumer satisfaction with public mental health services. Consumer participation in the public mental health field means that the service providers ensure consumers have the opportunity to influence decision making processes in the areas of service delivery, service planning and development, training and evaluation” (p.5)*

Central then to consumer participation is having a voice and an opportunity to influence policy and service directions within the mental health sector.

Prominent New Zealand consumer, Mary O’Hagan (1994), captured the essence of consumer participation, saying: “Real consumer participation is not just inviting the match to sit beside the matchbox, it’s getting the match and the matchbox to interact so that they will make something new – fire” (p.43). Further, McGuiness and Wadsworth (1991), and later Epstein and Wadsworth (1994) talked about the consumer perspective as “…a motor for change” (p.vi) through dialogue. Hence, the introduction of paid Consumer Consultants (CC) positions in Victoria’s public mental health services was a significant strategy for fostering dialogue, and creating a systemic mechanism through which consumers have a voice in mental health services to influence their quality and directions (Wadsworth & Epstein, 2001).

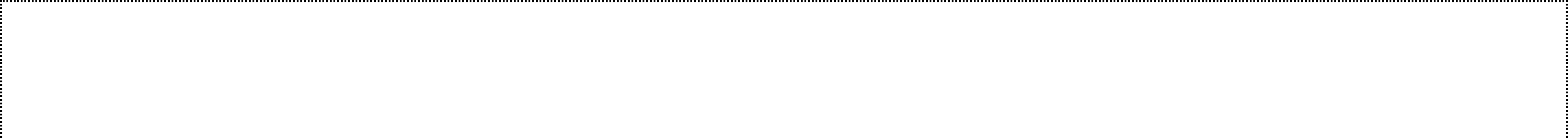
The current consumer workforce in Victoria predominantly comprises CC positions, usually funded by Department of Human Services (DHS), with some consumers working in roles related to research, education, training, peer support, advocacy, mentoring, supervision, and in Consumer Advisory Groups. Most consumer perspective work is being undertaken in Area Mental Health Services (AMHS) and Psychiatric Disability and Rehabilitation Support (PDRS) services for adults. Emerging consumer perspective work occurs in services for youth and older adults, Primary Care Partnerships (PCPs), other non-government organisations, DHS and universities, including one consumer-academic position (Happell & Roper, 2003; Roper & Happell, 2007). Additionally, some consumer workers undertake freelance consultancy, much of it with little or no acknowledgement (Stewart et al., 2008). Some incremental and ad-hoc growth has also occurred in the development of consumer participation projects in Victoria (see box below).

There are also identified needs to extend the scope of consumer perspective work in services for youth and older adults, with Culturally and Linguistically Diverse (CALD) groups and in rural settings (Burgess et al., 1999; Carr, 2005; DHS, 2002).



Some examples of consumer participation projects:

* Alfred Psychiatry Consumer Participation Program’s Staff-consumer collaboration in treatment (Kroshel, 2001)
* Consumer participation in staff selection panels (Grimshaw, 2003)
* ‘Our Consumer Place’, a resource centre for mental health consumer developed initiatives -see: [http://www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au/)



* Consumer Academic program, CPNRP, University of Melbourne – see: <http://www.cpn.unimelb.edu.au/about_us/consumer_academic>
* The Mental Health Legal Centre projects on consumer involuntary-treatment experiences with the Mental Health Review Board, and on Advance Directives

– see: <http://www.communitylaw.org.au/clc_mentalhealth/cb_pages/images/Lacking>

\_Insight.pdf <http://www.communitylaw.org.au/mentalhealth/cb_pages/living_wills.php>

* Consumer and Carer Experiences of Care Surveys, conducted by VMIAC and Network for Carers - see: [http://www.health.vic.gov.au/mentalhealth/quality/consumer.htm,](http://www.health.vic.gov.au/mentalhealth/quality/consumer.htm) [http://www.vmiac.com.au,](http://www.vmiac.com.au/) [http://www.carersnetwork.org](http://www.carersnetwork.org/)
* VMIAC Consumer Research and Evaluation Unit - see: <http://www.vmiac.com.au/research.php>
* Consumer peer support related projects at the Mental Illness Fellowship and Mind Australia

## Commitments in policy

*“There are three major rationale that support the development of the service user workforce in the mental health sector. Philosophically it is the ethical thing to do. On a pragmatic level it is the sensible thing to do. On a policy level it is the expected thing to do.” (Mental Health Commission, 2005, p.5)*

Consumer participation has been part of national and state mental health policies for some time (e.g, Australian Health Ministers, 1992; Department of Health and Community Services, 1996; DHS, 2002), as well as individual organisations. The existence of such policies demonstrates an acceptance of consumer participation and an expectation that it will be implemented at all levels of the sector.

For instance, the National Standards (Australian Health Ministers’ Advisory Council National Mental Health Working Group, 1996), against which mental health services (MHS) in Australia are accredited, state that: “Consumers and carers are involved in the planning, implementation and evaluation of the MHS” (Standard 3, p.10). As part of this standard, the MHS is expected to have consumer participation policies and procedures that maximize consumer roles and involvement in the service. They should also support activities such as advisory groups, meetings, training, provision of space and resources to maximize consumer participation.

In keeping with the above standards, the mental health workforce is expected to: *“actively promote, encourage and support the participation of consumers, family members and/or carers in the planning, implementation and evaluation of mental health service delivery.”* (Australian Health Ministers’ Advisory Council National Mental Health Education and Training Advisory Working Group, 2002, p.11).

At state level, the Victorian Government (DHS, 2002) acknowledges that consumers play a unique role as part of its non-clinical workforce in mental health. Its 2003 guidelines for the consumer consultant program described consumer consultants as an important means of enabling consumer perspectives to be included in the planning, delivery and evaluation of MHS, and stated:

*“Area mental health services should provide the consumer consultant with appropriate supervision, training, and professional development opportunities that support effective operation of the consumer consultant program” (DHS, 2003, p.1).*

Dr. Ruth Vine’s Foreword to the draft Action Plan for Consumer Involvement in Victoria’s public MHS too *“…reinforces the critical and unique expertise of consumers – the lived experience. It recognises that this ‘lived experience’ is needed to inform and shape practice across policy and service delivery, planning, development and evaluation” (DHS, 2007, Foreword).* This action plan also stated that a renewed commitment is needed to ensure that meaningful and sustainable consumer participation is embedded in the mental health system.

The Victorian Government’s 2008 mental health reform strategy consultation paper, *“Because Mental Health Matters”*, also recognised the need to build the CWF capacity so as to improve its effectiveness across mental health services, as well as “for strong organisational leadership to embed cultural change at every level of the mental health system – in management, planning and service delivery” (DHS, 2008, p.92). Therefore, there exists broad recognition that consumer participation is essential in MHS, and that a robust consumer workforce could change their face, culture and quality.

## From policy to practice

Consumer worker roles have diversified to respond to policy directions and to growing recognition that consumer perspective work improves the culture, quality, effectiveness and responsiveness of community MHS (Burgess et al., 1999; DHS, 2005; Grimshaw, 2003; McCann et al., 2006). There are noteworthy advances in the field of consumer perspective work. For instance, persuasive evidence of this can be seen locally from the evaluation of the development of Consumer Participation in Staff Selection strategy, of which Lyndall Grimshaw (2003) wrote:

*“Feedback from key stakeholders in the CPSS strategy indicated that the CPSS strategy was extremely well regarded by consumer participants, staff on panels, employees and senior managers and clinicians within the Northern Area Mental Health Service. The initiative appeared to have profoundly influenced the culture of the service, including factors like the quality of staff appointments, staff attitudes and practices.” (p.6)*

Another example of an initiative leading to further roles for the CWF is the *Review of the Victorian surveys of consumer and carer experience of public mental health services* (DHS, 2005), which recommended consumer organisations co-ordinate, recruit, train and support consumers to administer these surveys, or that MHS contract with consumers as survey administrators. Nevertheless, broad policy support for consumer perspective work as an integral feature of all MHS does not necessarily translate into practice (Pinches, 2004; Stewart, Watson, Montague & Stevenson, 2008). So, the scope for consumer participation has increased but its implementation has been variable across service settings (Lammers & Happell, 2004; Middleton et al., 2004), and significant barriers to its meaningful implementation persist.

On the whole, expansion of CWF roles and responsibilities have not been matched by increased funding, resources and infrastructure, with detrimental impact on the sustainability of consumer perspective work. Complicating this is the fact that consumer consultants often operate within service systems that neither necessarily share similar goals or values with the CWF, nor cater well for its resource,

supervision or training requirements (Middleton et al., 2004; Watson, 2007). Consumer advocates also often lament that many worthwhile initiatives rise, and later fall, on the basis of ad hoc, unplanned project funding that tends to lack integration with long term policy objectives.

A relative lack of evaluation of consumer participation work is noted in the literature (Campbell, 2001; Middleton et al, 2004), but there are some local examples. These include the evaluation of consumer participation in Victoria’s MHS (Burgess et al., 1999), the evaluation of consumers on interview panels for MHS staff selection (Grimshaw, 2003), and the development of tools to enable consumers to more fully participate in their treatment (Kroshel, 2001). Other studies provide evidence of the benefits of consumer involvement in staff training, and consumer-led or peer- provided programs (Clay, 2005; Doughty & Tse, 2005; Happell & Roper, 2003; Khoo et al., 2004; Simpson & House, 2002). Nevertheless, little attention has been given to consumer workforce issues (Mental Health Commission, 2005), and its absence suggests tokenism in regards to turning policy rhetoric into practice.

In their consumer training needs analysis, Stewart et al. (2008) concluded that:

*“To progress the mental health reform agenda, we need to move beyond the rhetoric of policy…into the realm of practice to address the persistence of stigma and discrimination and to effect the power shift required for meaningful consumer participation” (p.352).*

It is in the gulf between policy and practice that the issues affecting the development and growth of the CWF lie. The existing literature identifies some major obstacles to the continued development of the CWF.

## An overview of the major issues facing the CWF

The ‘Lemon Tree Learning Project’ undertaken by Merinda Epstein and Julie Shaw (1997) used the metaphor of the lemon tree to emphasize the importance of infrastructure and support for consumer participation. In this metaphor, the trunk of the tree is seen as the foundation for solid consumer participation nourished by ‘roots’ in a supportive infrastructure. The leaves and branches are the elements that connect and strengthen consumer participation, where *“… the distinction between the leaves, branches and roots is drawn not in terms of their content, but in terms of their process and situatedness”(p.22).* Drawing on this metaphor, the absence of fundamental infrastructure for consumer participation undermines the quality and strength of consumer perspective work. These main issues are discussed under the headings of infrastructure and resources, education and training, attitudes, and personal safety.

Infrastructure and resources

The under-resourcing and inadequate infrastructure supports for the CWF are prevalent themes in the literature (Happell & Roper, 2006a; Roper, 2003; Stewart et al., 2008; Watson, 2007). This includes lack of financial, material and human resources. For instance, Roper (2003), a consumer academic, reflected:

*“During the last decade, many resources, campaigns and consultations, committees and projects have been developed… But very few resources are ever given directly to consumers, to be used to create the kinds of vital infrastructure we need in order to participate [more safely] (p.5).*

Likewise, New Zealand’s Consumer Workforce Strategy 2005-2010 identifies that:

*“Many of the workforce needs of people filling these [service user] roles are unmet. They lack training, work opportunities, professional associations, well defined practices and favourable work conditions. These roles have the most urgent need for workforce development” (Mental Health Commission, 2005, p.10).*

Structural organisational support was also frequently identified as what consumer workers most needed to fulfil these roles in Stewart et al.’s (2008) survey of New South Wales’ consumer workers. Stewart et al. suggest that this under-resourcing of the CWF is problematic not only for consumers but also because it *“leav[es] services that employ consumers, or engage them in voluntary capacities, open to accusations of tokenism and exploitation”* (p.348). Consumer consultants interviewed in Middleton et al.’s (2004) study too identified the need for “better resourcing and support from DHS and local MHS” (p.515).

### Job structure and working conditions

The recent *Because Mental Health Matters* consultation paper (DHS, 2008) recognised the importance of investing in the mental health workforce and providing a “secure and supportive organisational culture, access to ongoing training and development opportunities and clearly defined career paths” (p.111). However, whether these conditions have been extended to the CWF is debatable, despite the policy commitments to consumer participation outlined earlier.

Basic infrastructure for good working conditions, such as clear job structures with well-defined job descriptions and responsibilities, pay scales and career paths are yet to be fully developed, or formalised for the CWF (Hansen, 2003; Happell & Roper, 2006a; Stewart et al., 2008; Watson, 2007).

Adequate and fair salaries

Pay parity and adequacy are ongoing issues for the CWF (Bennetts, 2008; Epstein & Olsen, 1998; Hansen, 2003; Happell & Roper, 2006a; Ryan & Bamber, 2002), with Stewart et al. (2008) finding one third of consumer workers were not paid at all, and almost half paid casually. Ad hoc, individually negotiated arrangements, and the absence of industry standards result in a lack of consistency in salaries at best; substandard wages and token or in-kind remuneration at worst.

Consumer worker views consistently indicate that the absence of job infrastructure and fair working conditions contribute to unclear role definition and job strain at work, and to financial and emotional stresses impacting their personhood and lives beyond work (Findlay, 2000; Roper, 2003; Stewart et al., 2008). These issues have been difficult to address as there is no professional representative body for the CWF.

### Funding

The issue of funding consistently emerges as an issue with wide-ranging impacts on job structures, sufficient allocation of EFT and remuneration, basic resource availability and project sustainability, and training opportunities (Burgess et al., 1999; Happell & Roper, 2006a; Stewart et al., 2008). Inadequate funding is also reflective of the broader issue of budgets not keeping pace with developments in consumer perspective work. As one AMHS senior manager quoted in the Allan Pinches’ (2004) Pathfinders report reflected: *“I would hope that the CC and consumer participation is funded in a way that keeps up with the enormous developments that are happening” (p.13).*

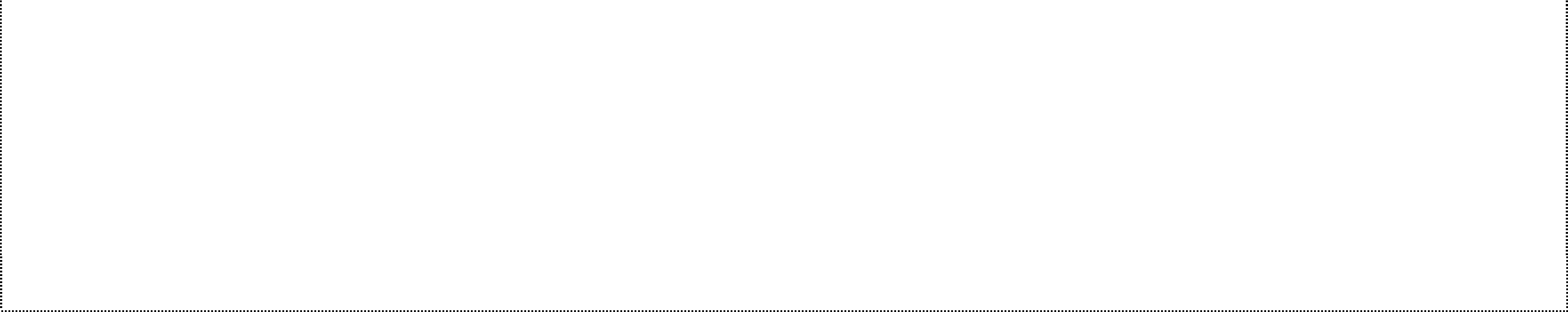
Education & training

Education and training covers a broad area with huge potential for effecting change in attitudes and knowledge informing service delivery and clinical practice in MHS. Training opportunities for consumer workers, as well as more time for consumer workers to be involved in community development, the education of mental health workers, and training for MHS staff and for managers remain markedly underdeveloped.

### Consumer perspective training for consumers

Initially, when consumer consultants were first employed in Victoria’s public mental health services, an induction program was provided (Wadsworth & Epstein (1996). This has not continued, and recently surveyed consumer workers in New South Wales reported being significantly under-prepared for their roles due to lack of training opportunities both when beginning and during working in this area (Stewart et al., 2008). Stewart et al. also reported wide-ranging ideas but no consensus on the content of training needed; there was however strong support for a code of ethics. This is consistent with debate in the CWF. Issues include the potential for education and training to become exclusionary if there was an academic pre-requisite; the potential course content; and how and by whom it might be delivered (Bennetts, 2008; Mental Health Commission, 2005; Stewart et al. 2008). The need for this area to be developed, though, is unequivocal and Epstein and Olsen (1998) recommended the most appropriate training for consumer workers is likely come from other consumers.

Access to ongoing peer supervision, mentoring and support for consumer workers constitute further neglected areas identified as particularly important for CWF development and (Bennetts, 2008; Roper, Stewart et al., 2008).



Successful education & training initiatives over the past decade include:

* VMIAC Consumer Consultant conferences
* Consumer participation workshops coordinated by the Health Issues Centre (La Trobe University)
* Publication of *The Kit: A guide to the advocacy we choose to do* (Spice Consulting, 1999)
* PAT (Psych Action & Training) group, CPNRP, University of Melbourne – see: <http://www.cpn.unimelb.edu.au/about_us/consumer_academic>

### Consumer involvement in education and training of MH professionals

The DHS (2007) draft Action Plan for consumer participation recognised the importance of consumer input into MH sector education. It is also acknowledged that consumers need to be better resourced to deliver training (Deakin Human Services, 1999; DHS, 2002; Ramon & Sayce, 1993). *Sight Unseen* (Roper, 2003a) is one such resource developed by Cath Roper for use by consumer educators. Happell and Roper (2003) too conducted a study to evaluate student attitudes to consumer-delivered education for nurses and found an overall positive impact on student perspectives and clinical practice. Other studies also suggest consumer involvement in staff education and training enhances attitudes towards consumers and consumer participation, as well as changing students’ perspectives and staff practices (Khoo et al., 2004; Tew et

al., 2004). Beyond this, consumer involvement in the education and training of mental health workers needs further development and evaluation.

*Consumer workforce involvement in research: developing skills & evidence* In services that value ‘evidence’, the lack of investment in developing a solid research base for consumer perspective work disadvantages the CWF (Campbell, 2001;

Stewart et al., 2008). Other barriers to CWF involvement in research include the

perspectives and approaches dominant in mental health research and attitudes towards consumers (Griffiths, Jorm & Christensen, 2004; Happell, 2008; Telford & Faulkner, 2004). Griffiths et al. (2004) suggest the need to build bridges between academia and consumers to enrich the psychiatric research culture, encourage collaboration, increase the relevance of research to consumers, and contribute to destigmatisation of mental illness. Telford and Faulkner (2004) also suggest increasing consumer involvement in research enhances the valuing of ‘expertise by experience’, asks different questions, and contributes differing understandings to inform services. In addition to these benefits, it would enable the CWF to build skills in conducting research and develop its own evidence base.

Attitudes

The intent of consumer participation and the establishment of the CWF has always been about facilitating change (Deegan, 1989; Epstein & Rechter, 1999; Findlay, 2000; Ramon & Sayce, 1993), of which fostering attitudinal change is an essential element (Wadsworth & Epstein, 2001). However dismantling attitudinal barriers requires collaborative efforts. For instance, Burgess et al.’s (1999) evaluation of consumer participation in MHS noted that when management make consumer participation a priority, clear systemic achievements were evident in practice. Middleton et al (2004) identified differing readiness for change in services, using the terms ‘Service Red’ and ‘Service Green’ to capture the elements of influence, stigma, tokenism and service culture that enable and disable opportunities for bringing about such change.

### Attitudinal barriers amongst MH professionals

The enduring barriers of discrimination and stigma in society are amongst the challenges that people who experience mental health issues continue to encounter in their daily lives. These issues also persist within the mental health sector and pose real barriers to effective consumer participation. Indeed, attitudinal barriers towards people experiencing mental health issues amongst health professionals are extensively documented (Epstein & Olsen, 1998; Kent & Read, 1998; McCann, Baird & Lu, 2006; 2008; Middleton et al., 2004). These can be overt negative attitudes, but also quite subtle and discriminatory. Others report that paternalism is often encountered by the CWF amongst their colleagues, who are mental health professionals (Middleton et al., 2004).

### Issues of power and conformity

It is suggested that consumer worker roles challenge the traditional power relationships that exist between consumers and health care providers, or shine a light on practices that may be problematic (Campbell, 1993; Epstein & Rechter, 1999; Kordes, 2001; Telford & Faulkner, 2004). These power differentials can generate tension in services and often consumers feel pressure to refrain from challenging

health professionals and silence themselves, rather than “rock the boat” (Medernach, 2000). As McAllister and Walsh (2004) explain:

*“When people complain about the system or attempt to change it as individuals there are mechanisms in place to silence them – through co-opting, assimilating, re- victimising them, or encouraging an inward gaze” (p.29).*

This highlights the importance of fostering respectful working across these power differentials (McAllister & Walsh, 2004; Wadsworth & Epstein, 1998).

### Valuing the consumer contribution

A further important issue is the devaluing of the consumer worker role in the mental health sector. This is attributed to the lack of understanding of, and respect for consumers’ lived experience, knowledge and perspectives (Happell & Roper, 2006; McAllister & Walsh, 2004; Stewart et al., 2008). Happell and Roper (2006) challenged the view that the CWF is not representative of all mental health consumers in carrying out their work. They suggest a “myth of representation” is used to undermine consumer perspective work and activism, as well as subjecting the CWF to a standard not expected of health professionals. They maintain that such scrutiny is an overt expression of the attitudinal issues that the CWF has to grapple with.

A flipside to this concern of ‘representativeness’ is the blanket treatment of consumer workers as one and the same, when in fact the CWF is vastly diverse:

*There is a tendency to homogenize differences – to see all people with differences as ‘the other’ to see problems rather than successes and to despair when ‘they’, the homogenized, do not react as they ‘should’ (McAllister & Walsh, 2004, p.25).*

This issue is linked to the tension inherent in working within a system whose philosophy and operations are grounded in a hierarchical, medical model so there is an expectation of some conformity to the dominant culture. It also raises a conflict of interests, at times, where consumer workers are advocating for systemic changes to the system that employs them (Casey, 2006). McAllister and Walsh (2004) suggest that this issue requires “Being aware of difference… acknowledging that the consumer role is not equivalent to the provider role and that there is value in having a distinction between the two” (p.26).

Personal safety

There are various risks and vulnerabilities tied to consumer perspective work, which Ross Findlay (2002) has framed as occupational health and safety concerns. He argued that consumer workers and employers have a joint responsibility to address issues of maintaining role integrity, work expectations and workload, and provide work conditions necessary to do the job.

### Maintaining role integrity

Burgess et al.’s (1999) evaluation of consumer participation in MHS recommended that well-defined job descriptions, responsibilities and adequate supervision could alleviate role confusion related to the parameters and scope of consumer worker roles in mental health services. In their absence, Watson (2007) suggests that consumer workers “*are caught up in a complex and sometimes toxic cocktail of role strain, role confusion and role conflict”* (p.4)*.* This potentially compromises the quality of work, the benefit to the organisation, and the personal safety of individual workers. It is

further compounded by “divided loyalties” (Casey, 2006), whereby consumer workers have to walk “the fine line…trying to maintain personal and professional integrity and credibility” (p.3), whilst trying to maintain accountability to health service management, colleagues, other consumers and themselves. This results in enormous strain on individuals and the consumer workforce.

### Work expectations and personal safety

In his Pathfinders report, Consumer Consultant Allan Pinches (2004) observes that, while there have been achievements towards more consumer-friendly services these positive outcomes ironically put a great deal of strain on consumer consultants. So, the demands of consumer perspective work become disproportionate to the resourcing, and often consumers are forced to put in extra hours, otherwise important goals might not be achieved at all (Roper, 2003; Pinches, 2004):

*“There are also widespread accounts of Consumer Consultants trying to maintain large outputs of work, within an already complex and demanding role, in some cases striving to personally “bridge” service gaps, and often facing costs to their own health and wellbeing”(Pinches, 2004, p.24).*

Ultimately then, a situation is created in which the more effectively work is conducted by consumer workers, the more consumer perspective work is perceived to be needed in other areas of the service, thus increasing demand. However, as Pinches (2004) wrote:

*“…there are limits to how far this equation of self-sacrifice by consumer consultants can be pushed and services could be argued to have a special responsibility to be aware of this – partly because of the inherent power imbalances in the employment of consumers as change agents within a system which has a range of impacts on them and others, and the somewhat open-ended and ‘challenging’ nature of the work” (p.11).*

Hence, McAllister and Walsh (2004) noted, “the employer should provide support, a safe environment and regular feedback on performance” (p.30) to ensure the personal safety of workers. However, as outlined earlier, this support is not always available.

### Workload & vulnerability

Watson (2007) described the vulnerabilities particular to consumer perspective work, which can have a potentially negative impact on consumer workers:

*“Many consumer workers suffer extensive psychological and emotional distress as a result of undertaking consumer employment within settings in which consumer work becomes the default option to satisfy policy imperatives. Default award. Default job title. Default job description. Default tasks. Default training…They are under siege” (p.11).*

For the CWF, the ‘retriggering’ of personal circumstances is noted by Kordes (2001), Epstein and Shaw (1997) as a risk inherent in the very nature of consumer perspective work, particularly as it pertains to automatic disclosure and added pressure to tell personal stories (Medernach, 2000). Medernach writes,

*“Unlike some advocates, I have been very reticent in terms of telling personal stories and past history. Personal stories are important, but if that is all we are allowed or encouraged to contribute, it almost amounts to the same old message: tell me your problem, I’ll fix you. My personal preference is to focus on issues and solutions.*

*Although I occasionally use personal experiences as examples, these are usually limited to relevant current situations…” (p.227).*

These vulnerabilities mean that there is a considerable risk that members of the CWF will “burn out”, without a change to the current culture of expecting more, and without any substantial increase in resources and inadequate workplace support structures, such as peer supervision. It would be ironic if the price of consumer-led culture change in mental health services turns out to be damaging to the consumers doing the work.

Despite the above range of disincentives and barriers, consumers demonstrate real commitment to the values and promise of this work. However, the participation of consumers in the CWF could be enhanced by better infrastructure and support for CWF roles, improved informal support networks and creating more opportunities for CWF research (Cleary, Walter & Escott, 2006).

Fostering participation and leadership

Consumer leadership draws strength and legitimacy when it emerges from within the community of interest and remains accountable to this constituency (Victorian Quality Council, 2007). Currently, consumers rarely hold positions of power and influence in the mental health sector (Kent & Read, 1998; Lammers & Happell, 2004). Sarah Gordon (2005) argued that the influence of consumers will remain limited unless they are involved at every level of organisations, as called for in national and state policies. She maintains that *“the actual realisation of consumer involvement within the MH sector is extremely variable and the extent of ‘real’ participation…questionable, particularly in relation to power influencing positions” (p.36)*. Therefore, the development of a culture of consumer leadership in MHS is essential (Gordon, 2005).

Relatively little has been written about mental health consumer leadership to date. However, the Victorian Quality Council (2007) identifies the need to promote and support consumer leadership across the broad health sector, so as to ensure effective engagement with health professionals and services. Further, Happell and Roper (2006) argued that by “identifying the existence of consumers as leaders, there is acknowledgment of a movement to be led, of interests to be served” (p.6).

In conclusion, the major issues facing the CWF include infrastructure and resources, education and training, attitudes, and personal safety. These issues impact upon the clarity and integrity of consumer worker roles, the opportunities for advancement, development and long-term sustainability of consumer perspective work for individuals and the CWF within the broader mental health workforce.

In light of “t*he apparently ad hoc and haphazard evolution of these roles”,* Stewart et al. (2008) ask “*to what extent is authentic consumer involvement being enacted?” (p.349).* This study then aimed to increase understanding of the issues facing the CWF and in doing so, to identify its needs for infrastructure, support and resourcing for sustainable development.

# Research Design

This study was designed to explore consumer workforce issues in the mental health sector, through consumer-led, participatory and qualitative research methods.

*Consumer-led* research is driven by a consumer perspective, grounded in direct personal experience of mental health issues and mental health services. It draws on expertise in the consumer body of knowledge, which is a body of information, knowledge and wisdom about the kinds of experiences that consumers commonly have, the nature of the services system, language or ‘discourses’, and the historical situation of consumers (Wadsworth & Epstein, 2001).

Consumer workers undertaking this research for themselves, as opposed to it being undertaken on their behalf, was an important guiding principle in the design of this research. This was achieved by the establishment of a project reference group which met monthly and guided the design and implementation of the project. The group comprised seven members of the consumer workforce in positions within academic, clinical and PDRS sectors, as well as the consumer peak body, Victorian Mental Illness Awareness Council (VMIAC). Three members from mental health disciplines were included to provide a range of relevant expertise on research and mental health workforce issues and to support research capacity building within the project team.

*Participatory research* is a collaborative approach which involves key stakeholders in guiding the direction of research, the questions and methods used and their implementation (Fossey, Harvey, McDermott & Davidson, 2002). People employed in the consumer workforce in the mental health sector are well placed to be actively involved in shaping research focused on the consumer workforce because they have relevant and direct experience of working in these roles. Further, people who participate in health & medical research have the right to participate not just as subjects, but as partners in the design, implementation, dissemination and reporting of research (NHMRC & CHFA, 2001).

*Qualitative methods* are useful when there is little known about the target group’s perspective (Rice and Ezzy, 1999). This approach has been popular in consumer research because it aims to understand participant perspectives on the experiences under study.

Ethical approval was obtained prior to commencement of this research from the Melbourne Health’s Mental Health Research and Ethics Committee.

## Participants

All participants were mental health consumers working to provide consumer expertise either within Victorian public MH services and PDRS sector organisations, or through casual work or independent consultation. Participation was intentionally sought from people in diverse roles, including consumer consultants, advocates, academics or trainers, and peer support workers. The majority of participants were working in adult services; none were consumer workers in youth and aged services. In qualitative research, the purpose of selecting a diverse sample of participants is to ensure a wide range of views on the topic are represented (Fossey et al., 2002). In participatory research, this diversity also helps to counterbalance the guiding input of the Project Reference Group.

Mental health workers (e.g., doctors, nurses, allied health professionals etc) who experience mental health issues (disclosed/undisclosed) but are employed in non- consumer service provider roles were excluded from this project. The size of this project did not permit exploration of this important group and is worth considering in future projects.

Recruitment

Focus groups were chosen as an appropriate method to gain an understanding of the perspectives of consumer workforce members, followed by further in-depth interviewing to enable further exploration of specific roles or emerging issues. Hence, recruitment occurred in two phases.

* 1. *Focus groups:* Expressions of interest for participation was initially sought via email. An email (expression of interest and Participant & Information Consent form - attached) was sent to members of the consumer workforce through VMIAC and PDRS sector consumer consultant distribution lists. This was done with the assistance of Project Reference Group members involved in these organisations. Five focus groups were conducted.
  2. *Interviews:* Following the focus groups, the Project Reference Group identified some specific CWF roles and issues less extensively represented in the focus groups, and people who could be approached for an interview about them. Some potential participants had also indicated their interest in being interviewed at the time of recruitment for the focus groups. Four individuals were purposively selected, and approached for interview.

Therefore a total of 24 people participated in interviews or focus groups. All participants were fully informed of the purpose of the research in a plain language statement. Participation was voluntary, and all participants gave written informed consent.

## Data collection procedures

Development of questions for focus groups and interviews

The focus group and interview questions were based on the literature review, and built on the questions developed for a TheMHS conference workshop facilitated by Cath Roper and Wanda Bennetts. These questions served to initiate dialogue with the Project Reference Group, and were further modified before using them in the focus groups and interviews.

Focus groups

The focus groups sought to enable the views of a broad range of consumer workers in education, advocacy, consultancy and CAG roles in metropolitan and rural services. The focus groups were conducted by members of the reference group – two facilitators for two groups, three facilitators for one group and one facilitator (the lead researcher, Wanda Bennetts) for the fourth group. Each group lasted one to one and half hours.

* Participants were provided with sample questions beforehand (attached to the plain language statement) and informed that they were not required to answer questions that they did not want to answer.
* Participants were also advised that they could take a break or discontinue their involvement at any time, if they wished to do so. Likewise, in the event that reflecting on one’s work circumstances could raise uncomfortable feelings, participants were offered assistance with making their preferred arrangements for support.

Interviews

In-depth interviews were used to further explore the themes that emerged from the focus groups. In-depth interviews are commonly used in qualitative research because they are “an excellent way to discover the subjective meanings and interpretations that people give to their experiences” (Denzin, 1989, p. 67)*.* Their flexibility also allows for a change of direction if something new begins to emerge during the research process. They give scope for participants to include issues that are important to them, which might not have been considered by the researchers and would otherwise be missed in a more structured approach with predetermined, fixed questions.

Wanda Bennetts conducted the interviews, which were one to one and a half hours in length. As with the focus groups, participants were provided with sample questions beforehand, and provided with the same information regarding answering questions, taking breaks, discontinuing their involvement and support arrangements.

Recording the information gathered

With participants’ consent, focus groups and interviews were tape-recorded and transcribed to facilitate qualitative data analysis. Also, detailed notes were taken. The quality of the tapes was poorer than expected and not as useful as the note taking, since participants could be given the opportunity to view the notes along the way and make comment, clarify or delete anything that they wished to.

* Participants in focus groups and interviews were also informed that they would have the opportunity to review, comment on and withdraw any information from transcripts or notes taken if they so wished.
* Pseudonyms were used to ensure individual participants, as well as specific organisations, were not identified in the transcripts, findings and reports from this study. In the focus group recordings, it was not always clear who was speaking. Therefore, sometimes participants were not given a pseudonym.

## Data management and analysis

Focus group and interview data were analyzed thematically.

* Initially, Wanda Bennetts and Allan Pinches from the Project Reference Group independently read and sorted the focus group and interview data, each generating a list of main themes.
* They cross-examined these two lists for commonalities and differences.
* A list of themes was then presented to the Project Reference Group for discussion and comment. A concept-mapping technique was used in the course of the Project Reference Group discussion to identify the links between themes and organise the themes into a coherent framework.

The authenticity of qualitative research findings is enhanced when members of the CWF can recognise their own experience represented in the themes (Rice & Ezzy, 1999). So, the involvement of two consumer researchers in initially sorting the data into themes, as well as the involvement of other consumer workers in the Project Reference Group to refine these themes, each helped to enhance the authenticity of the findings.

Reimbursement

All participants were reimbursed for their time and travel expenses, and payments for consumer workers on the Project Reference Group were built into the project’s budget. These payments were funded through the DHS Mental Health Research Fellowship supporting this study. This practice is consistent with recommendations on consumer participation in health research (National Health and Medical Research Council & Consumers’ Health Forum of Australia, 2002; Sozomenou et al. 2000) and previous consumer-led research in the mental health sector (Wadsworth & Epstein, 2001).

# Findings

Five major themes in from the focus group and interview data were identified:

* The Essence of Consumer Work
* The Dollars
* Pathways: Education, Training, Supervision and Mentoring
* The Workplace
* Leadership

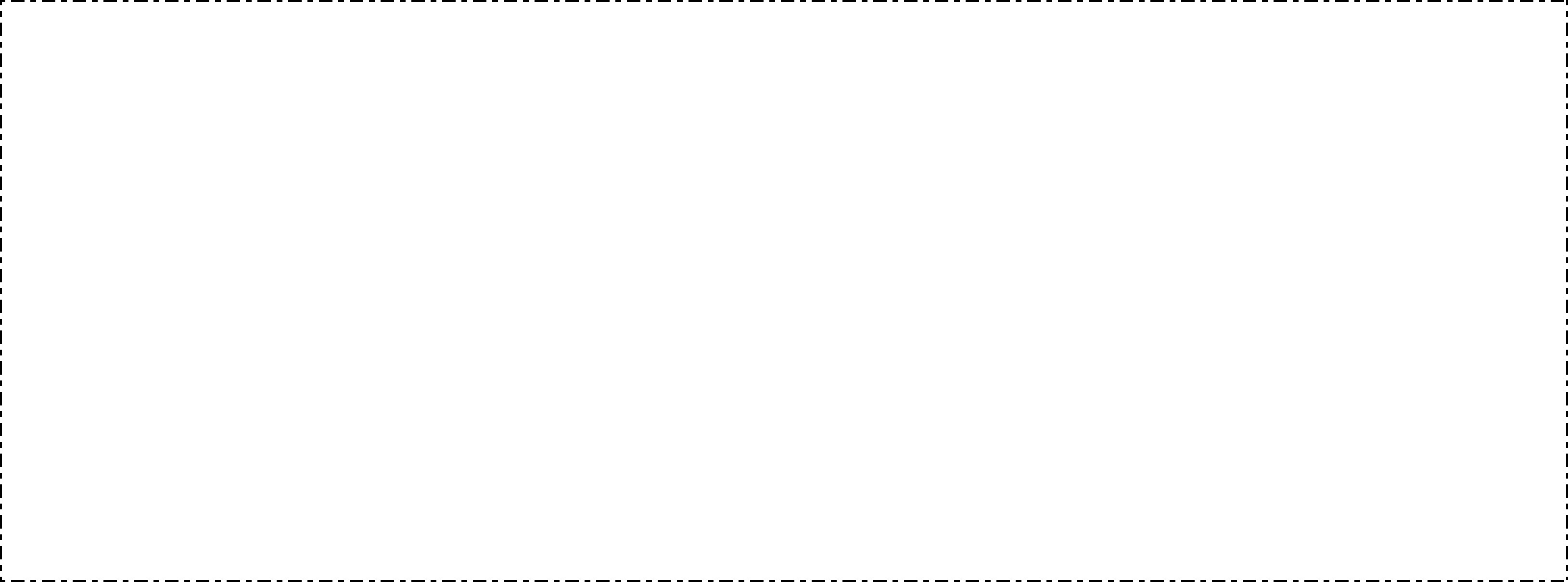
Each theme is supported by participant quotes.

## The Essence of Consumer Work



*“I think the consumer perspective is a special one, because people are so different, it is quite hard to always be able to cite a single unified consumer evidence based position that covers everything and everyone…It is about culture change but in some ways it is being able to demonstrate the effectiveness of what consumer consultants can offer if given greater resources, given more time and given more support and perhaps more freedom to pursue agendas over a wider area and to be able to set their own course.” (Arnold)*

Participants valued the roles that they occupied within the CWF and cited both positive and negative drivers for doing this work. For some, motivation came from having had ‘bad’ experiences that they hoped to change for others in the future. Some participants wanted the system to change or their own experiences to ‘mean’ something. Additionally, some participants felt strongly about addressing the broader agenda of stigma and discrimination within both mental health services and the broader community.



*“I’d been through certain things myself. I felt able enough to work and help people through similar scenarios – make a difference.” (Participant from Focus group 2)*

*“Instead of waiting for things to change in the system, I went to the system.” (Participant from Focus group 2)*

*“I couldn’t find anyone in the whole Mental Health Service who wanted to listen to me. I wanted that opportunity. Silencing is not only part of the problem, it becomes the issue.” (Participant from Focus group 1)*

*“To break down stigma” (Participant from Focus group 1)*

Participants spoke about a strong commitment to the work and valued the sense of belonging to something ‘unique and special’. CWF involvement was about being part of something ‘bigger’ than themselves, but also being in a job where people felt understood and valued.



*“It’s not just a job. It’s being part of a movement that’s important to me. I stay because of the people.”(Participant from Focus group 2)*

*“It’s a luxury to work in an environment where people have similar experiences. It’s great to work with people who “get it” (Bob, Focus group 2)*

The diversity of the CWF was reflected in the range of roles held by participants and their years of experience – one participant had spent twenty five years as a consumer advocate; one participant was attending the focus group on his first day in the role. This list demonstrates the breadth of work (both paid and voluntary) that participants had been engaged in:

*Education & training:*

* Community and peer education
* Providing a consumer perspective at mental health clinician training
* Qualitative research projects

*Committee work:*

* Executive level work
* Involvement in service development committees
* Implementing consumer satisfaction surveys
* Committee membership

*Consumer workforce & service development:*

* Line management and supervision to the CWF
* Involvement in consumer participation planning

*Direct activity for consumers:*

* Running consumer-only focus groups, advisory groups, meetings and forums
* Visiting consumers on inpatient units, in community settings and PDRSS settings
* Facilitating cultural, self help and recreational groups
* Unofficial peer support & advocacy work

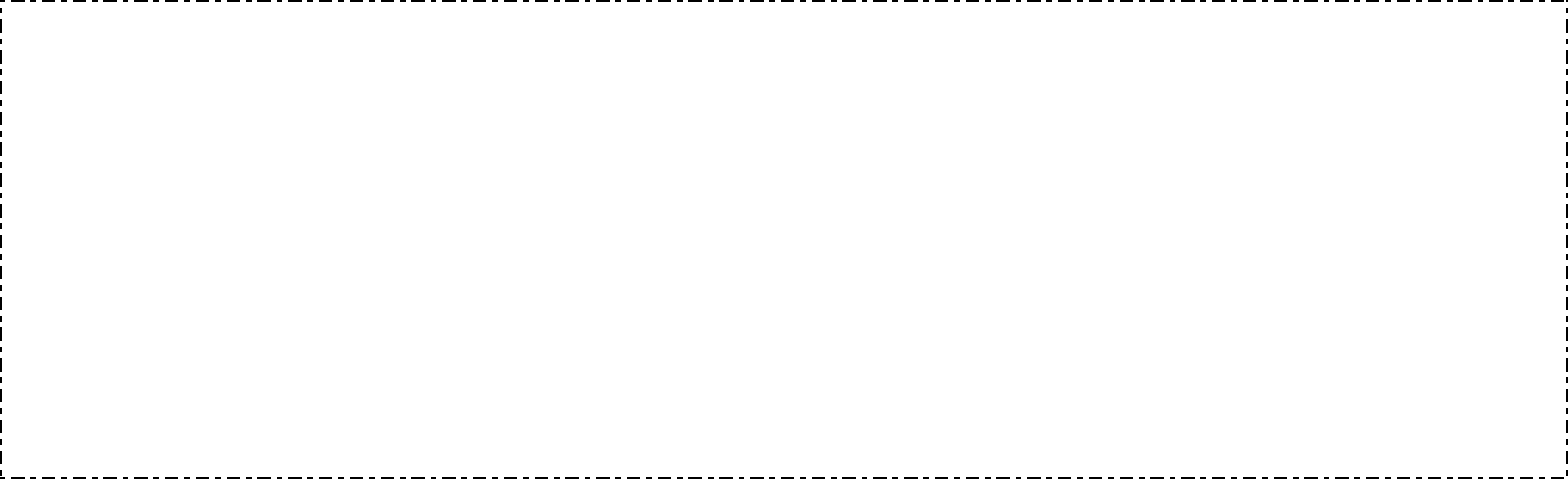
Participants highlighted roles within the CWF that need to be grown, supported or enhanced. There was discussion about further developing consumer education and training roles, particularly at undergraduate and professional development levels. It was seen to be a very positive and potentially powerful contribution by the CWF.



*“It is good when we do training providing a consumer perspective for nurses and other professionals. This sort of work should be part and parcel of the curriculum, not just in post graduate courses, but before they (clinicians) get into the workforce.” (Participant from focus group)*

Involvement in research was another area identified as underdeveloped: *“Two areas we haven’t influenced enough yet are policy and research” (Kate).* The value of a robust academic body of knowledge strongly grounded in people’s ‘lived experiences’, on which to base work being undertaken by the consumer workforce, was raised, as was the importance of including consumer perspectives in research being undertaken across health disciplines.

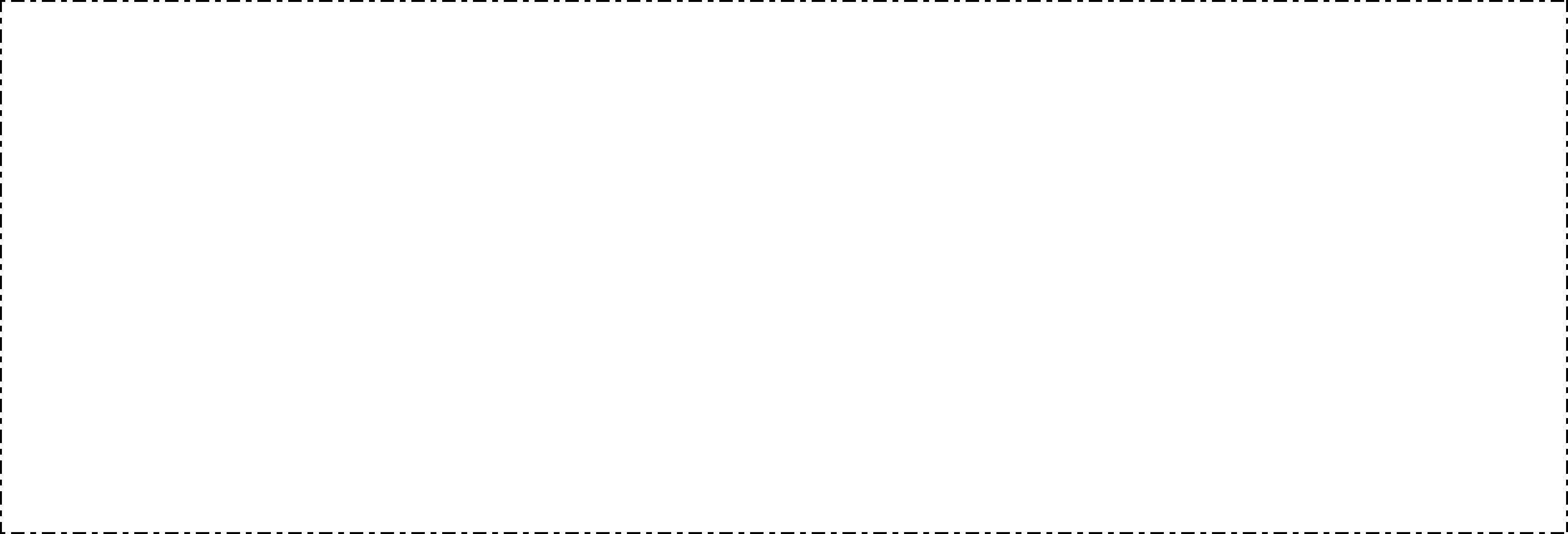
Some participants spoke of the need to increase and fund consumer positions in the PDRS sector, or suggested that the CWF should be looking at work in the wider community not just confining themselves to MH services.



*“I definitely see a role for the Consumer workforce who go around to agencies in the community such as Centrelink, health agencies, banks etc. It would be an interesting response from them. It has to be more on the agenda because stigma is the big thing. For example, you go to Centrelink and hear things like “That person’s schizo” and it puts you back.” (Renee)*

*“Also things like CCs in supported workplace services as well. They do a lot of assessments on people with mental illness and they don’t have the gist of what the person is about.” (Participant from Focus group 4)*

The casual nature of consumer perspective work was also highlighted as essential to CWF roles. The casual workforce refers to consumers, such as CAG members, who do work committee work, one-off projects, guest lectures and so on. Many consumer consultant positions are filled by individuals who have entered the CWF through this type of involvement. Being part of this network provides a space where consumers can talk to each other, share ideas & experiences and discuss their work in a safe and supportive environment. This is an enriching part of consumer perspective work largely because the CWF is such a diverse group of people, although they are often perceived as a homogenous group with a united stance. This casual entre into the CWF is a critical stage for new consumers who would like to work in the area. For this reason, participants felt that it was critical to nurture and support this core element of consumer work.



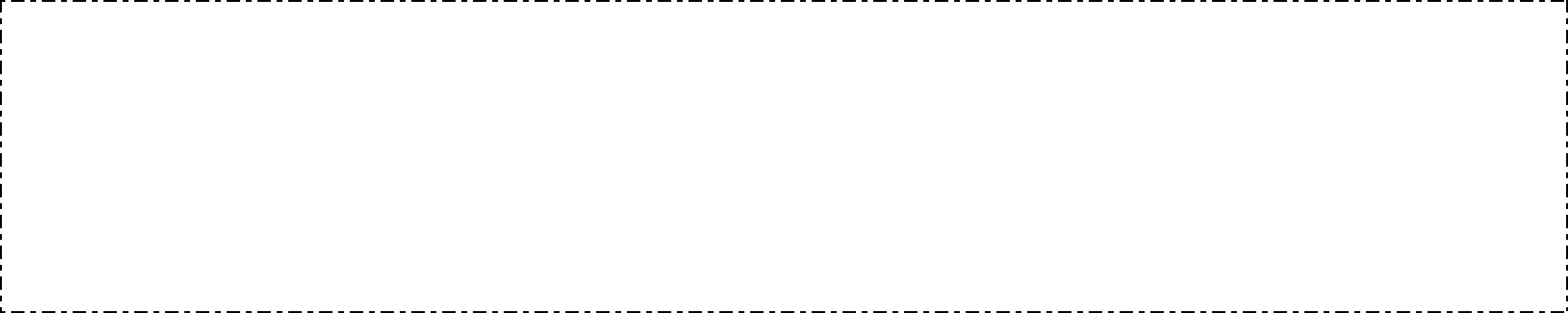
*“Consumer reps work at a more casual level, extremely important and consumer consultants would not be able to do their work without them… There should be lots of opportunities for them. If they do not receive opportunities then they are lost.” (Arnold)*

*“I think that I have been becoming a part of a 'mutual support' network of consumer workers…which gives me a lot of encouragement to continue doing what I am doing, reduces the stress associated with it, and gives me a bit of mentoring. And when things are going well the work can be fun and satisfying.” (Peter)*

## The Dollars

While no research questions directly targeted the issue of pay, this was continually raised by participants.

Money was not a motivating factor for people undertaking consumer work, however participants felt that payment was symbolic of being valued and recognised.



*“We are constantly told how important it [the work] is but we are not backed with remuneration.” (Participant from Focus group 1)*

*“Its not going to solve all the problems but it would go a long way towards making the CWF feel supported and valued. The problem is that we don’t feel valued because we are not properly paid and resourced.” (Vicki)*

Yet it was felt that despite considerable evolution and expansion of the CWF and its responsibilities over the past decade, there had been no ‘real’ increase in funding (especially for CCs) either in terms of pay rates of overall expenditure within the sector. As one participant put it, *“The base pay has hardly gone up at all. It’s one tenth of one per cent.”*

An important and powerful message about ‘real lives and real jobs’ emerged in this theme. Part time, low EFT and low paid work was not sufficient for every day living. There are scarcely any full-time positions available, and those wanting or needing more work have to change careers or juggle multiple jobs. This situation was identified as being problematic not only for individuals, but for maintaining a stable workforce. Consumer perspective work is often treated as a stepping stone to other work rather than a career in itself, and this can contribute to high turnover within the CWF or deter people from applying for these jobs as they cannot afford to work part- time. At the same time, not all people want or can work full-time. Therefore it was suggested that a mix of full and part-time positions should be on offer for people to fit with their needs and lifestyles, as is available in most other workforces.



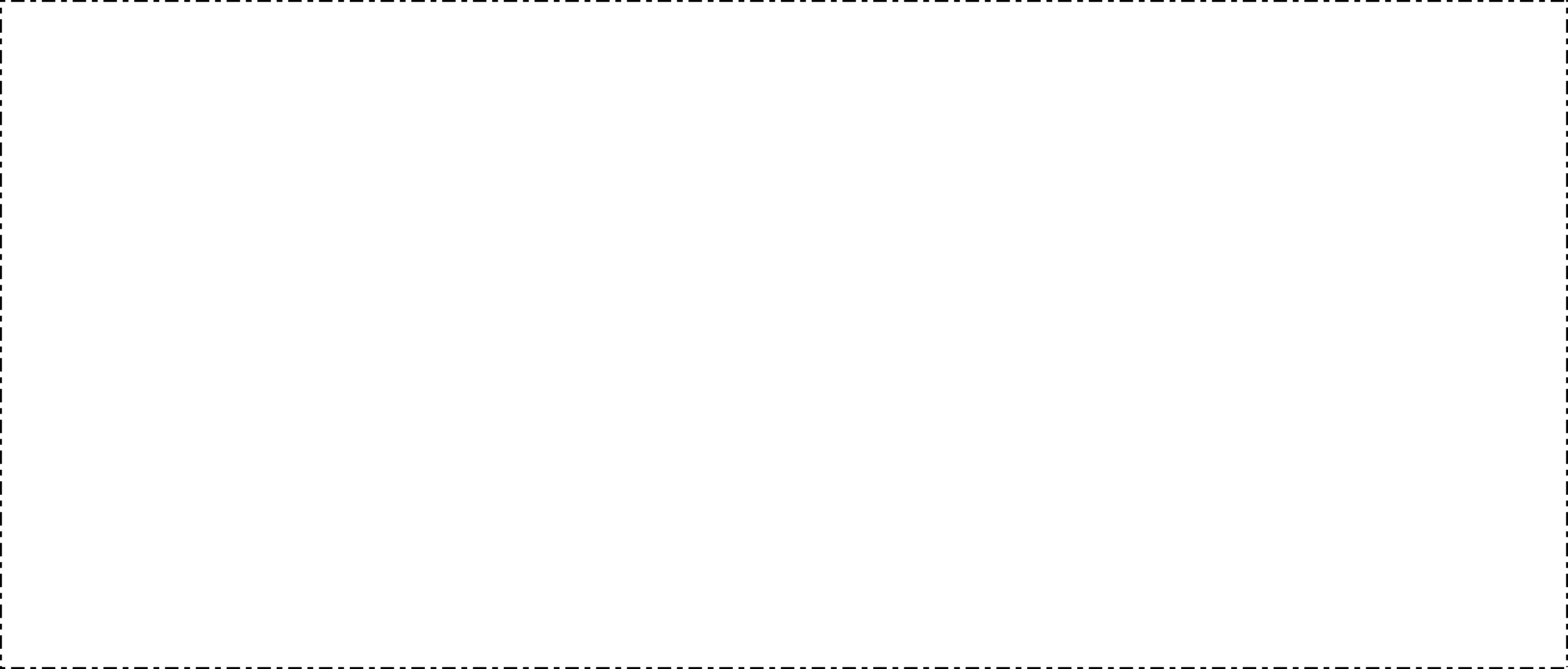
*“I’m supporting a family and the cost of living is high.” (Participant from Focus group 2)*

*“Many people, if they want more money, they leave Consumer Consultant work.” (Participant from Focus group 2)*

*“We need full time options for people and the hourly rate is pathetic. Not even being able to offer full time is a problem. We are not funded for EFT, we are funded a lump sum. This lump sum has only had CPI increases in the last 10 or 11 years...”(Vicki)*

*“It (part time work) gives some flexibility and necessary limits on the work.” (Participant from Focus group 3)*

Another related issue that participants raised was the consumer workload. CCs and others in the CWF often worked many hours above remunerated hours, sometimes at a personal cost. There was also an example cited of a CC giving up some of the CC budget dedicated to his own salary.



*“Funding is quite inadequate but enormous amounts of work are done in their own time, at great risk to their own physical and mental health; quite ironic that we are there to improve the situation for mental health consumers.”(Arnold)*

*“It is taken for granted that we are a very dedicated group of workers, greatly appreciated but perhaps not always an awareness of how much of ourselves that we are putting into these things.” (Arnold)*

*“The main challenge with work is making it compatible with my health management needs. This is the primary reason why some of what I do is self- employment - so I can control the workload and scheduling, and allow it to fluctuate if necessary…” (Peter)*

CWF pay levels were also discussed at length. The participants referred to their hourly rates and pointed out that there are virtually no options with regards to career or pay scales. Once in the job the only pay increase, regardless of experience or qualifications, is based on the CPI. Within the CWF, wage parity rarely exists; even those in roles parallel to others in the mental health workforce (eg, executive committee positions, education and training, project work) did not receive equal pay conditions. In some instances, there were still reports of consumers being paid with vouchers instead of being properly remunerated.



*“Career structure? Even if you do the job well, there is no possibility of that being acknowledged financially.” (Participant from Focus group 1)*

*“Rates of pay need to be OK compared to others in the organisation.” (Participant from Focus group 1)*

*“Pay rates for Consumer Consultants should reflect experience, longevity in the role and level of responsibility.” (Participant from Focus group 3)*

Some participants felt that there should be payment for experience and specialisation. Payment tied to formal qualifications was a controversial topic explored further in the ‘Pathways’ theme (see page 28).

Participants also talked about addressing the pay issue and focused on how to change it. The need to establish professional bodies, awards and unions to advocate for better conditions was raised several times. These structures were also seen as critical to maintaining the CWF.



*“There is a need for a minimum engagement fee. There seems to be an assumption that consumers have nothing else to do but just sit around. A nurse, for example, would not be employed for a shift of less than half a day.” (Participant from Focus group 3)*

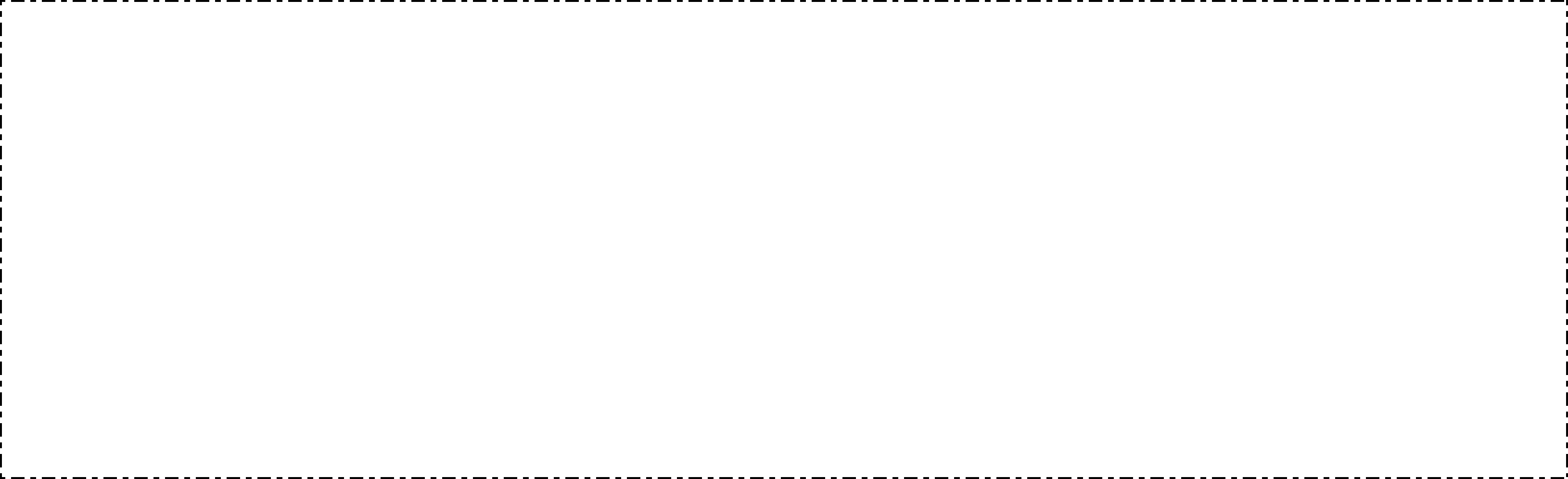
*“Who is advocating for the pay and conditions of the consumer workforce?” (Participant from Focus group 3)*

*“There is no professional body to negotiate. For example, when doing a talk, you accept gratefully what they give you.” (Participant from Focus group 3)*

*“… We don’t even have a common award, let alone an appropriate award. We recently lost a carer to another hospital because they offered more money....*

*Other things awards offer is study leave, penalty rates, career structures etcetera. Career structures – first of all they acknowledge experience in the workplace and secondly that provides sustainability in the workforce, because a good award and conditions encourage people to stay ” (Vicki)*

Another financial issue that participants raised was related to their involvement in budgets. There were few examples of consumers who had managed or had any control over their own project or position budgets. There was a sense of frustration that without this control there was no flexibility to respond to valuable opportunities; to direct funds where necessary; or to pay for basic items such as stationery. This is discussed again under the “Environment” theme.

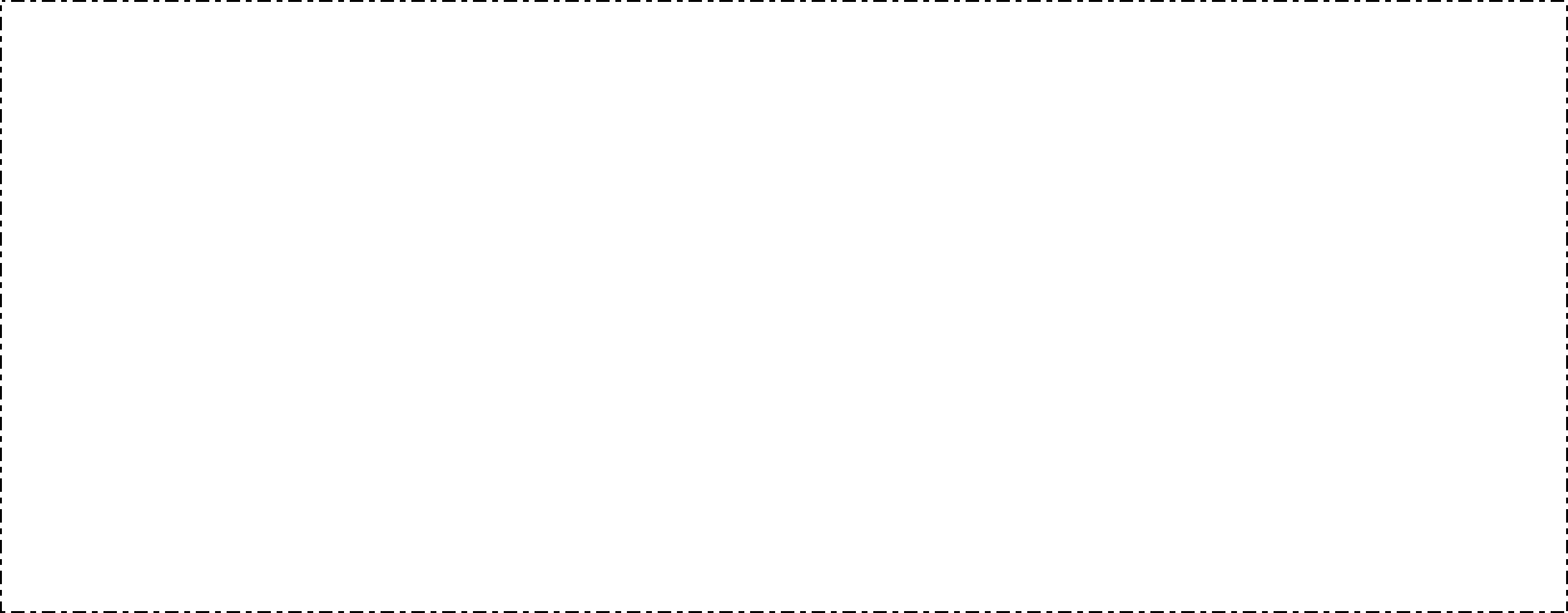


*“A budget gives opportunities to act.” (Participant from Focus group 2)*

*“Not having discretionary funds – having to beg, borrow and steal resources (even for items such as pens & paper). At one point, one manager gave me money out of his own pocket because I couldn’t claim something… Not getting enough funds for a CAG, but then being told I had to have a CAG … but I held firm and said I wasn’t having a CAG if I couldn’t pay them. That was a difficult position to take and then I was criticised by other consumers as well for not having a CAG.” (Vicki)*

## Pathways: Education, Training, Supervision and Mentoring

The theme of education and training was possibly the most contentious amongst participants. While participants agreed that education and training should be available to the CWF, there was no consensus about the content of the training and whether it should be compulsory. Historically, the ‘lived experience’ of the consumer has been the sole ‘qualification’ required for the CWF. No formal qualifications or training have been required, or even available, in order to take on this work. The early consumer positions offered an orientation training package to new consumer workers but other than this, there has been limited ad-hoc training available. Several participants suggested that a solid orientation program and initial training was imperative before undertaking consumer work.



*“Taking up this role. It’s a first and I never had a chance to ‘act up’ into the role beforehand like many staff get to do before taking on roles. There was none of the usual preparation work that usually happens for people. It’s a new role and it has teething problems and there is a lack of acknowledgement of that.” (Vicki)*

*“I think CCs would remain on the job for longer periods of time if they had training.” (Participant from Focus group 4)*

*“Training should be encouraged, to the point that if they are not prepared to take on training, then it should be part of whether or not they are selected for the job.” (Arnold)*

Underlying this was the importance of developing consumer perspectives as a unique and distinct body of knowledge. Most participants agreed that any future CWF education and training should be developed and delivered by experienced members of the CWF (or CCs).



*“What is needed is a more sophisticated notion or discipline”. (Kate)*

*“A dedicated curriculum needs to be developed by someone who has knowledge and knows the role – a consumer. A person who knows the service system.” (Participant from Focus group 3)*

Some participants felt that education and training for the CWF should be academically oriented and others were very concerned that this would make it exclusionary and inaccessible.



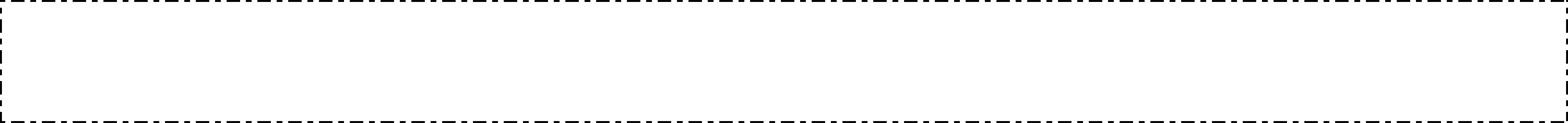
*“I don’t want it to be exclusionary - to have other hurdles like training.” (Participant from Focus group 1)*

*“There are good CCs who couldn’t cope with study, but do an excellent job.” (Bob, Participant from focus group 2)*

*“Skills and qualities – come from the lived experience.” (Participant from Focus group 3)*

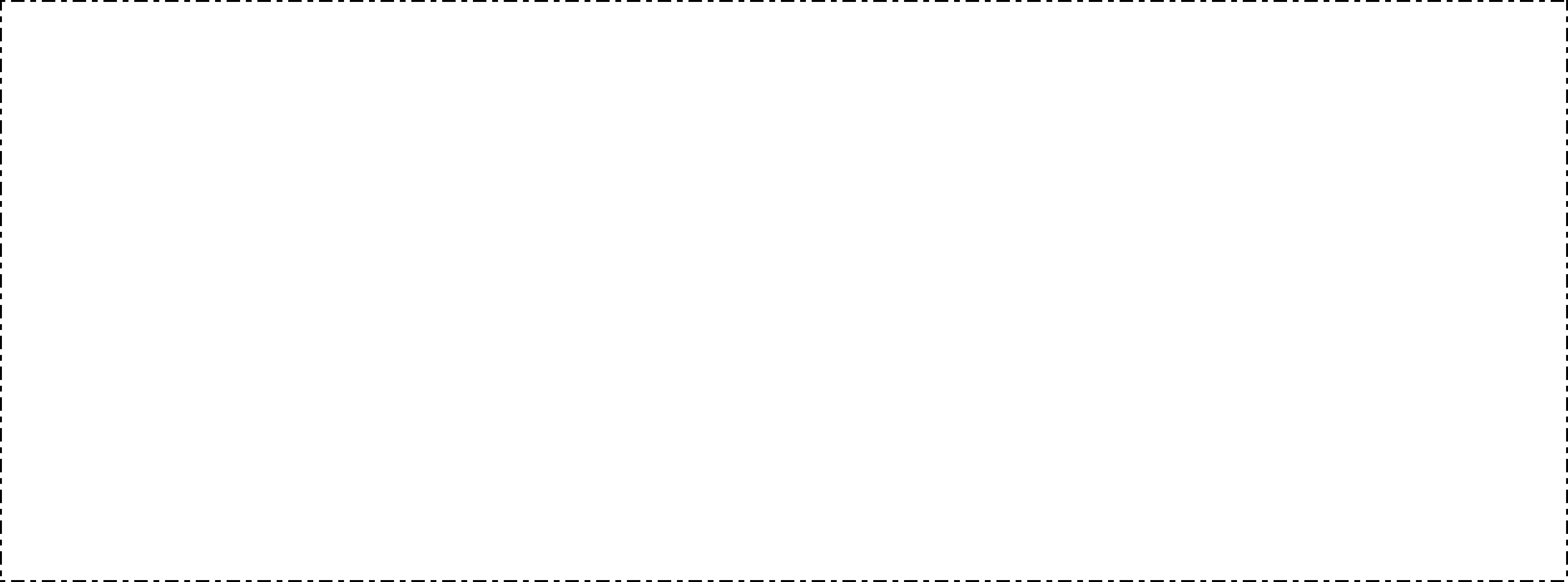
These participants felt that education and training should be based around supporting the lived experience of individuals in ways that develop each person *“…as they go…” (Participant from Focus group 1),* and that training should occur, *“…not at entry point, but along the way” (Participant from Focus group 1).*

It was unclear, though, how training should be made available to the CWF and which providers should be responsible for it.



*“Training should be provided free. On the pension I couldn’t afford it. My kids’ shoes come first.” (Jenny, Focus group 3)*

Ongoing professional development for members of the CWF was another issue raised, particularly in regards to supervision. Mentoring, peer support and opportunities for talking with others in the CWF to develop more ‘reflective practice’ were considered hallmarks of the CWF culture. Supervision and reflective practice were seen as important for providing opportunities to problem solve, to avoid isolation and to ‘feel safe’. Peer supervision – formal or informal – was a popular option, though some indicated that they were happy to receive supervision from ‘consumer friendly’ work colleagues. These opportunities were also valued for their contribution to personal development.



*Supervisors should:*

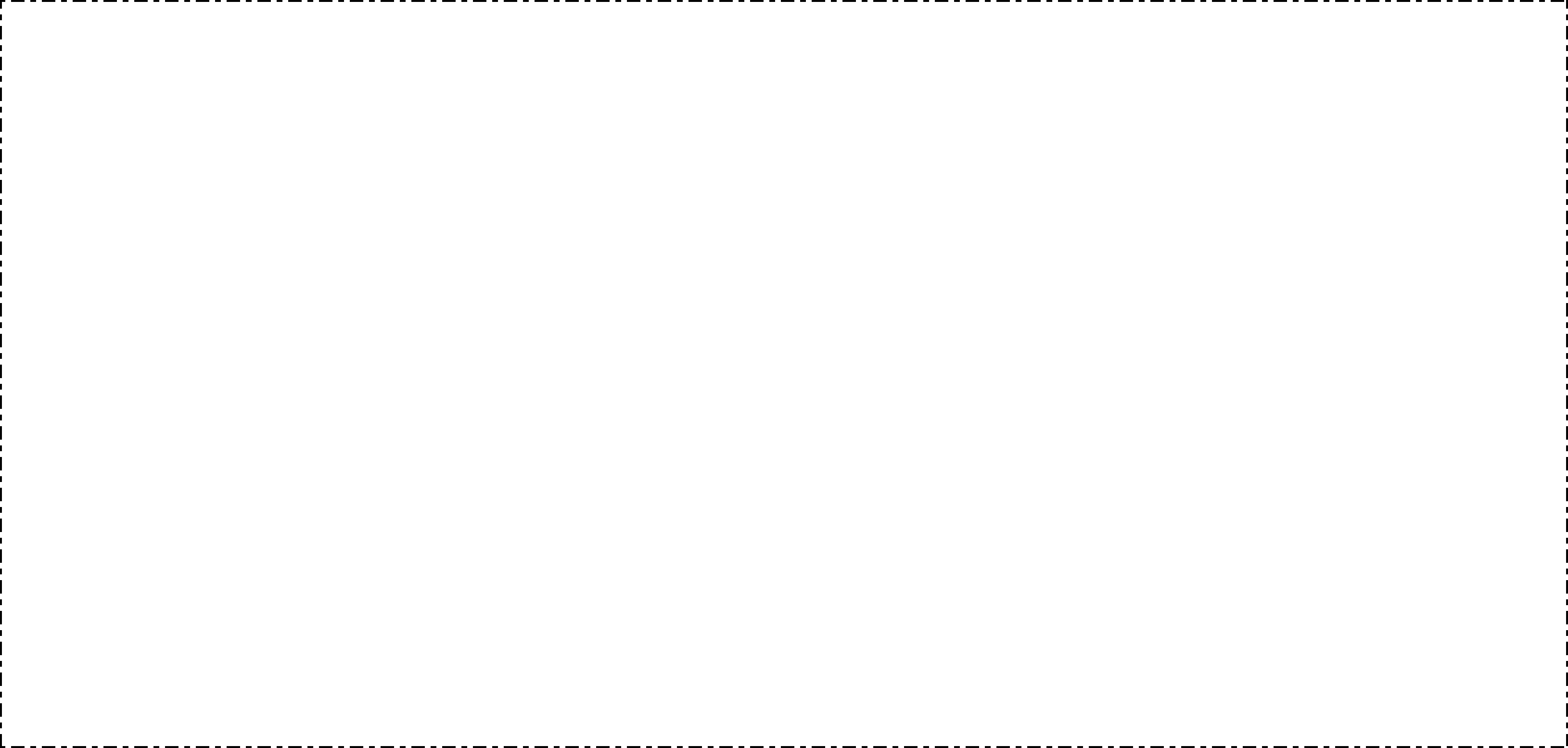
*“…be chosen by individual[s] and paid time provided to do this.” (Arnold)*

*“…have an idea of why you’re employed in the first place” (Participant from Focus group 1)*

*“Mentoring can be a very valuable way of people getting supported in these roles with other colleagues - someone they have known along the way, to help to stay afloat in a complex and difficult environment…” (Arnold)*

*“Mentoring, but not being told who your mentor is by someone else. Sometimes a mentor may not even know they are a mentor.” (Vicki)*

Ongoing professional development was also considered important for understanding organisations and building the capacity to do consumer perspective work.



*“The first couple of years was like beating my head against a wall because I didn’t understand organisational change and culture.” (Participant from Focus group 3)*

*“It’s frustrating. We need training in organisational change management and understanding legislation and strategies” (Participant from Focus group 3)*

*“I want to try to build in consumer participation without me. If it depends on one person it will eventually fall down. We need a perpetual model. The group could step up and do the facilitation of the lot.” (Jack, Focus group 3)*

*“Capacity building – yeah, that’s important. It is. The mental health music network, such as the Bipolar Bears, build capacity through this sort of thing. I see them as part of the consumer workforce, both formal & informal. They get the message out there.” (Renee)*

Another area that emerged under the theme of pathways, related to training and capacity building for non-consumer staff. Participants noted that orientation to the consumer worker role was important so that MH clinicians could understand what the CWF is about. There was a general sense that the CWF role was not well-understood and so long as this was the case, CWF roles would be considered peripheral to the general staff body. Here too there was no consensus on the details of such training.



*“Consumer Participation should be part of induction, orientation & training of all new workers.” (Participant from Focus group 1)*

*“There is no understanding of my role.” (Participant from Focus group 1)*

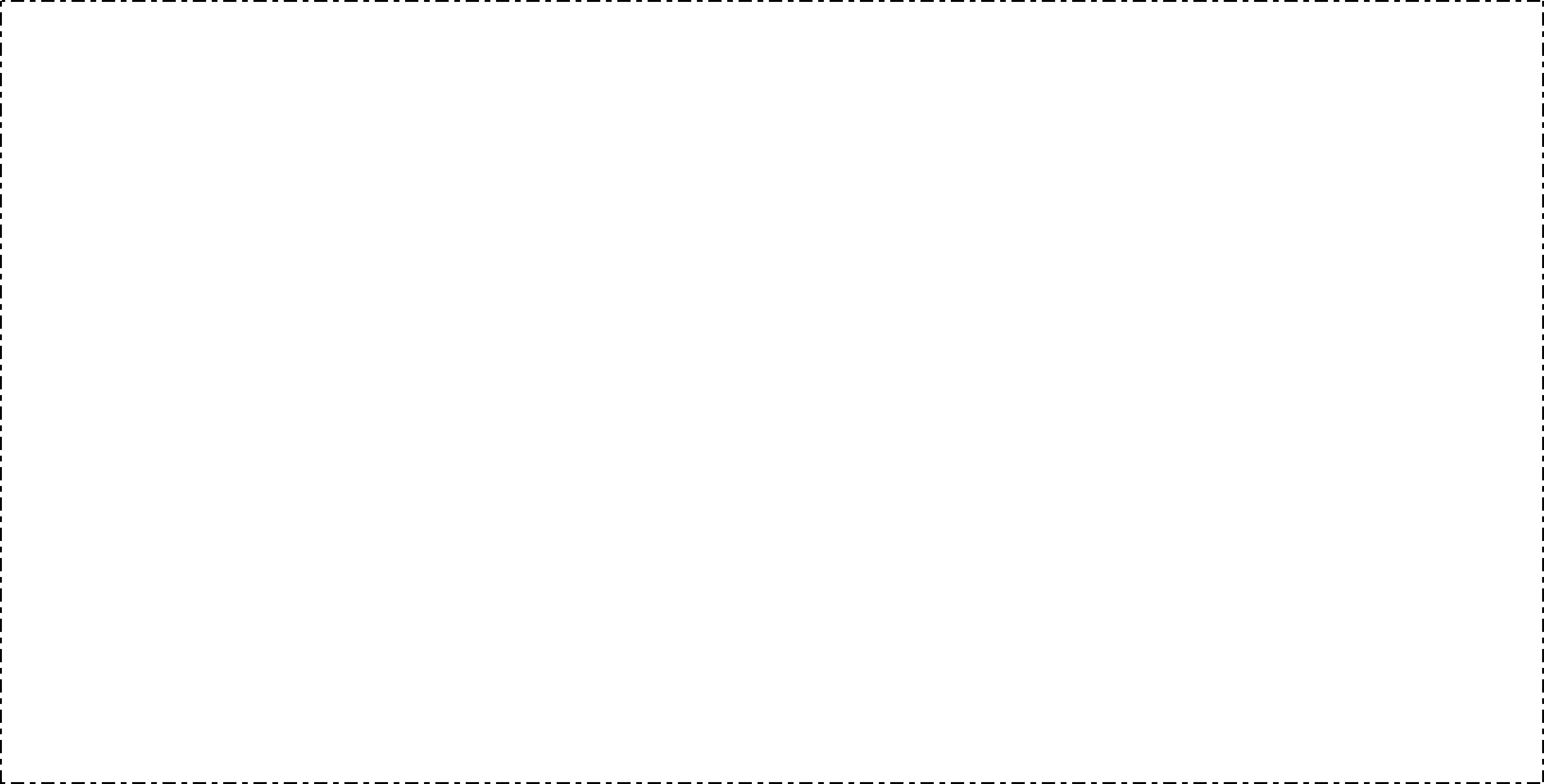


*“There is not enough education to professionals that consumers are staff members” (Participant from Focus group 2)*

*“It’s an organisational issue. They need to understand what we do.” (Participant from Focus group 1)*

## The Workplace

Participants provided many examples of how the environment impacts on their work. Flexibility, opportunities for reflective practice sessions with colleagues and peers, sharing the positives or good work examples so that others can see what is possible and having real opportunities to develop careers paths were all noted as valuable.



*“It’s important for organisations to support us by giving us more flexibility, more hours and to expect that there will be times when we can’t work.”. (Participant from Focus group 1)*

*“A plan for how we go if we get unwell an AD (Advance Directive).” (Participant from focus group 1)*

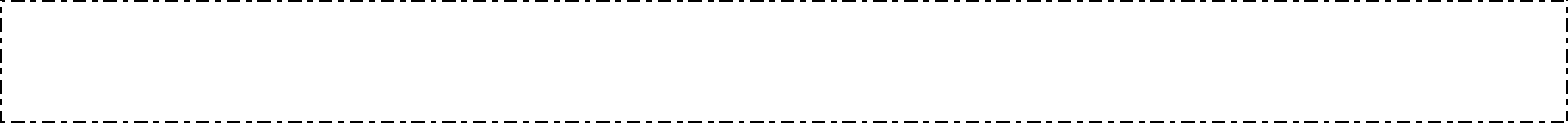
*“Promoting good work”. (Participant from Focus group 1)*

*“It always helpful when we can find ways to exchange ideas. We need to promote achievements - document and write up more of what we do.” (Participant from Focus group 1)*

*“Flexibility and respect, such as being able to work from home - as long as job gets done that should be OK.” (Participant from Focus group 1).*

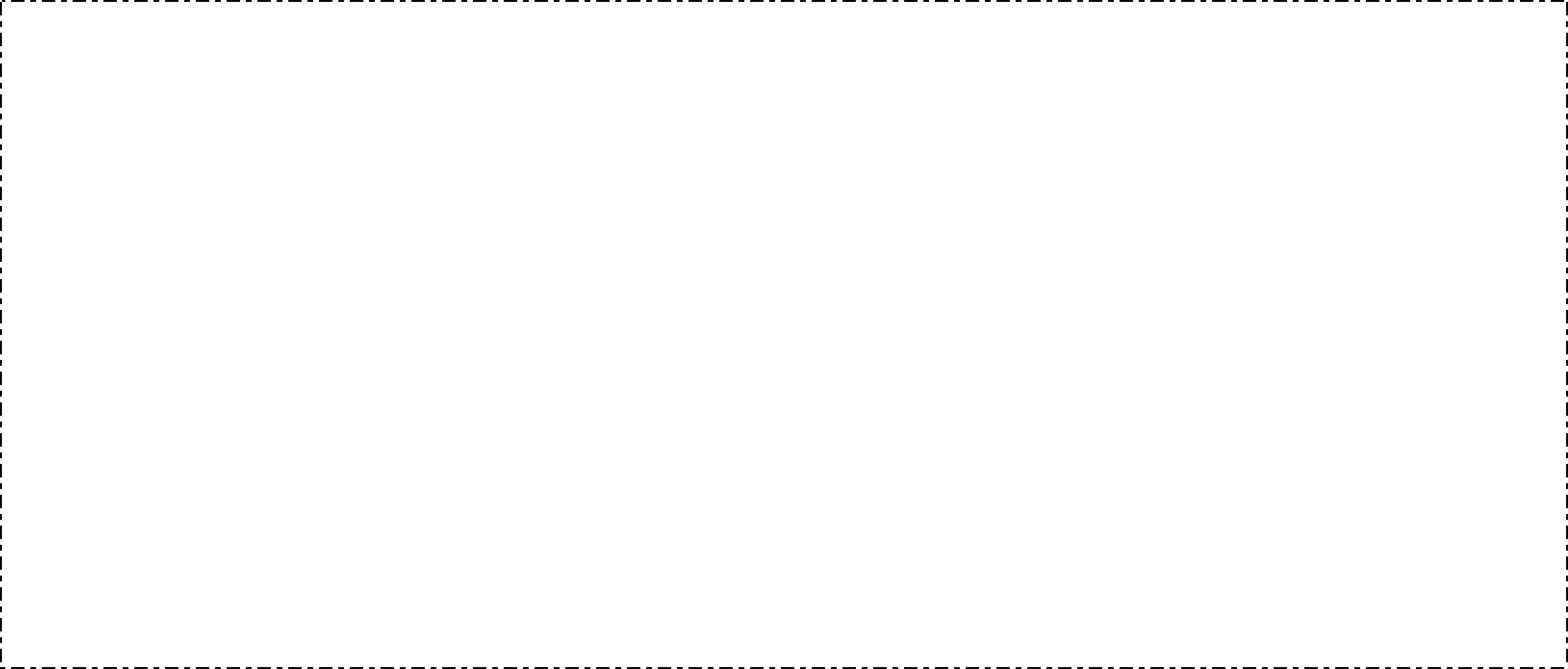
*Career paths: “I’d love one thanks.” (Participant from Focus group 2)*

Participants also raised some of the major barriers to getting their work done and feeling supported in doing so. On a material level, consumers were frequently frustrated by the inadequacy of basic resources such as stationery and space.



*“We need tools to complete the job such as mobile phones, lap tops…” (Participant from Focus group 1)*

The lack of well-developed job descriptions was noted as a barrier to better defined CWF roles and responsibilities, which in turn impacted on how consumer workers felt as contributors to the wider workforce. In addition to the content, how job descriptions were developed and who had input into their development was considered to be important.

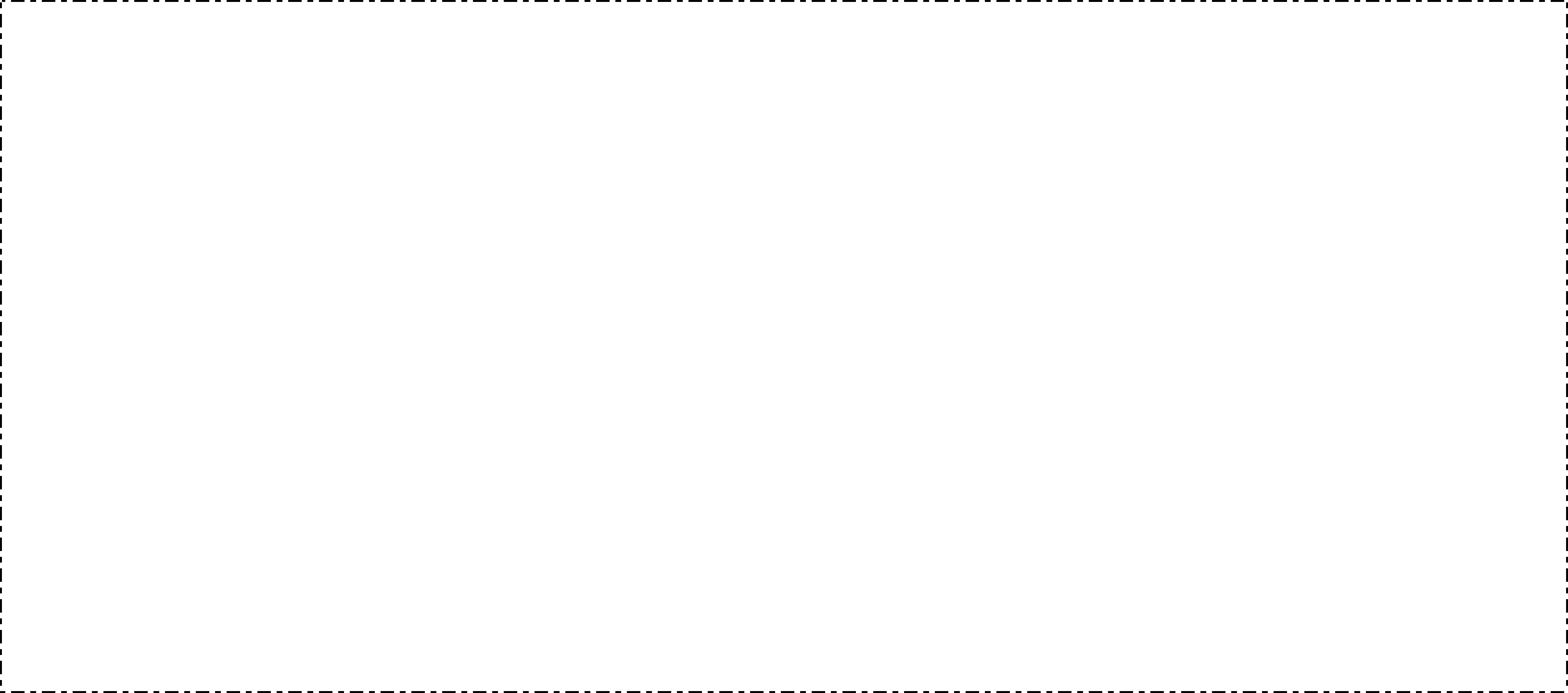


*“Job descriptions need to be more clearly defined. I was asked to rewrite my job description.” (Participant from Focus group 1)*

*“Consultant job descriptions can actually negate or limit consumers setting agendas, but can also provide welcome direction. Job descriptions can also allow for flexibility and leeway.” (Participant from Focus group 3)*

*“More planning, more structuring of the workload, getting clear with the service provider, and with the line manager what exactly do you want me to do. What time are you allowing? Let’s get realistic about the time involved. What do I now drop or delegate to others? They need to work out what goes out the other side. For each new thing, something needs to be put into the retired.” (Arnold)*

Another more complex issue was related to pressures of the work and the attitudes faced by the CWF on a daily basis. Pressures and attitudes were reported as having the most negative impact on doing consumer work.



*“The main challenge is being taken seriously by the rest of the organisation. It really bugs me that the reality of the job is we’re not taken seriously.” (Vicki)*

*“A significant amount of what we do is tokenistic.” (Participant from Focus group 1)*

*“The power dynamics are not addressed.” (Participant from Focus group 1)*

*“Within the mental health scene, the attitudes just seem to be worse than in the general community – the doctors, nurses etcetera…Stigma is the big thing*

*…but I feel I am accepted as part of the team. They’ve gone out of their way to make me feel comfortable. My boss is very comforting and supportive”. (Renee)*

Participants were concerned about the potential of these environmental factors to impact on the personal safety of the CWF.

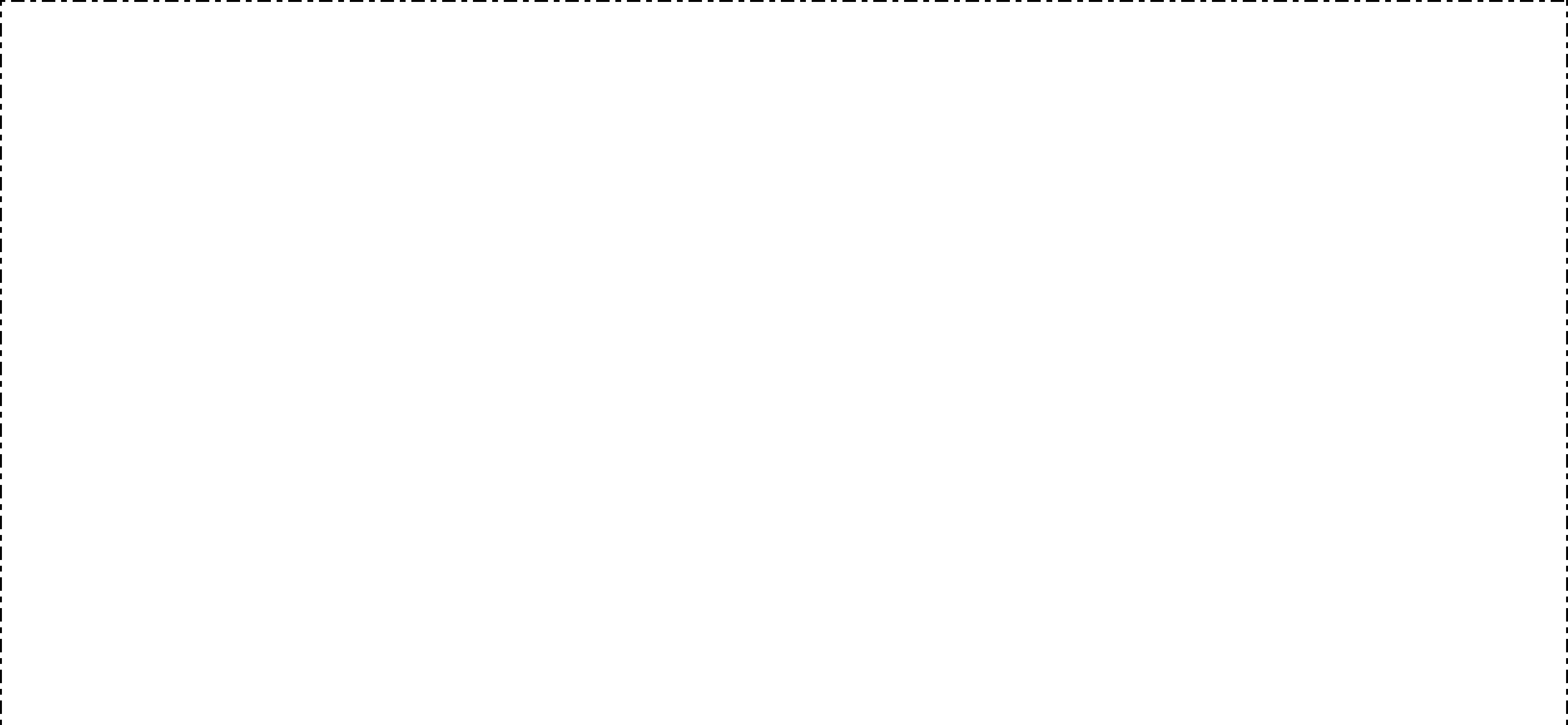


*“Personal safety – this is one of the biggest tensions in the work. I don’t want to do anything if it feels unsafe… It’s enough to say I feel unsafe. It’s about perception – if you feel unsafe, you are…” (Vicki)*

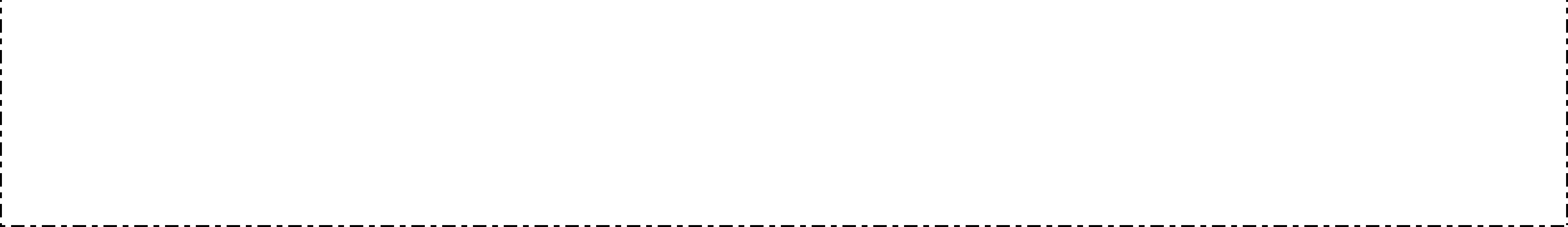
*“Personal safety is an issue for all consumer consultants as in these jobs there is a really high attrition rate. The tendency they are unsafe due to the large and fairly unregulated workloads, influenced by a low level of time and resources, work outside of working times, long hours overall, strain, tiredness, feeling of uphill battle, people say repeatedly running into a brick wall, not being heard, becoming frustrated, the person with illness can be touched off by this type of work. In partial remission, work can trigger a relapse. Depression can happen, old symptoms can revisit.” (Arnold)*

*“There is safety in numbers.” (Participant from Focus group 1)*

*“I pulled back on talks because I was disclosing more than I was happy to disclose and the people listening to the talks were pushing me to disclose more than I was happy to disclose.” (Renee)*

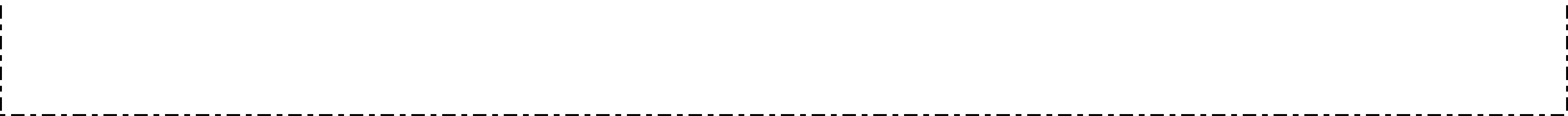
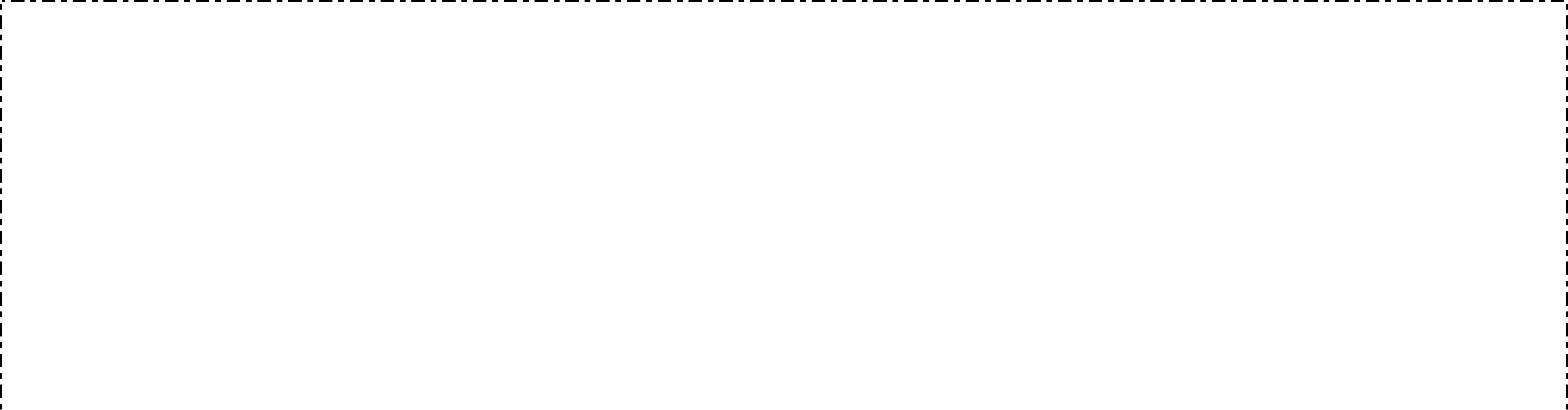


*“Isolation can lead to constant questioning of what you are doing which is undermining”...Safety’s got to do with the identity of the person and the worker. The person and the worker are so intertwined. That’s why for many of us this is such an issue. Its’ a very uncommon situation in work. If work is part of your identity and related to the experiences you have had, there are so many ways it is central to your identity. Things happen or affect you at personal level, not just a work level...There is no space to be someone who is more than offended – it is a non tenable position when you know rights have been breached, wrong has been done. You have to be the holder of morality and ethics and that can do damage if you are in a culture that is insensitive to rights. How do you work within that and still preserve that? You verge on being complicit which is a form of personal endangerment. In the end, I couldn’t live with myself… I was also told in no uncertain terms that my job*



*was on the line if I spoke out. That is bullying…We have to have debriefing more inbuilt to make it safer. Work in pairs is also essential. We don’t have to work the same days, but we need some overlap and someone you can phone or mechanisms in place where you are not left holding the shit bag.” (Kate)*

Finally, the need for transparency and accountability were central to this theme of environment. Participants often reported concern that services are not held accountable for supporting consumer participation and the CWF, and that this needed to change.



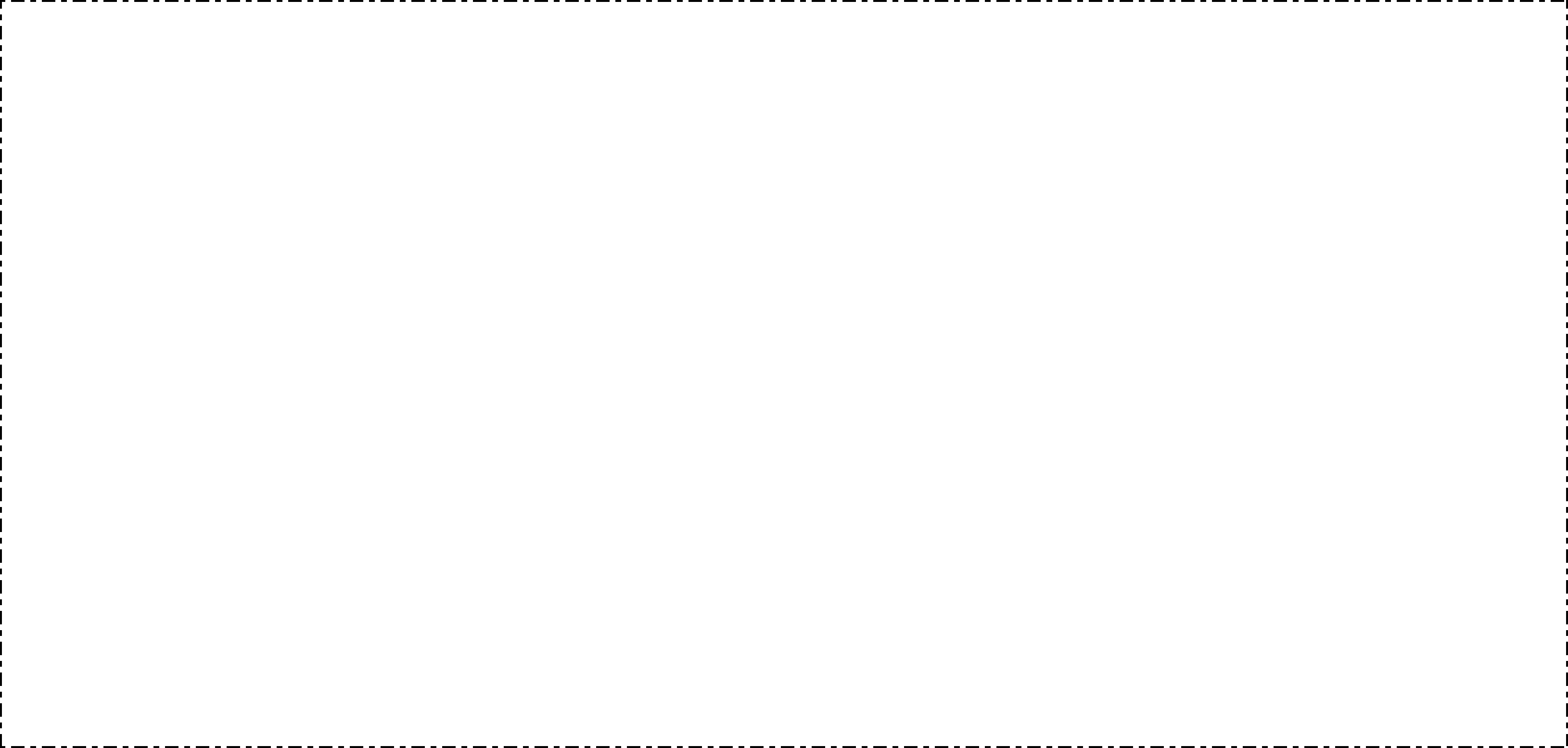
*“Services need to be held accountable too – to change.” (Participant from Focus group)*

*“If they don’t allow mutual accountability, they don’t really want consumer participation.” (Participant from Focus group 3)*

*“Consultation isn’t enough to call consumer participation.” (Participant from Focus group 3)*

”*… We have a single KPI and that is to say that they have employed a consumer, but there are no penalties for not achieving that KPI...” (Vicki)*

At the same time, consumer workers felt that they should also be accountable to consumers using services for what they do. This accountability may come from expanding the CWF presence within services, and from incorporating another layer of consumer perspective work, which occurs through consumer workers working independently of services.



*“Consumer consultants have been doing in some instances what is easiest. This doesn’t improve anything in the system.” (Participant from Focus group 3)*

*“I feel that I am accountable to consumers.” (Participant from Focus group 1)*

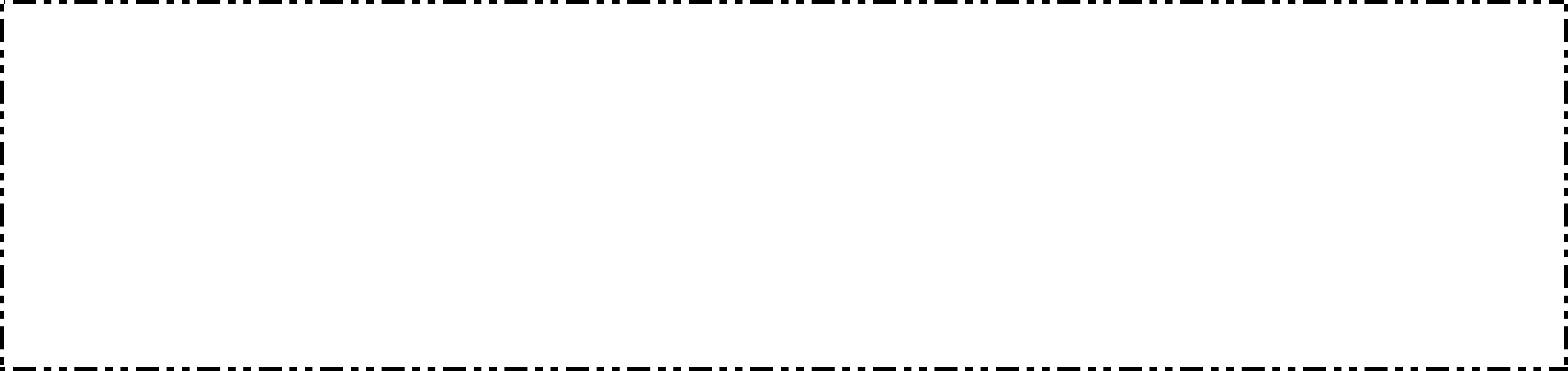
*“Having a large consumer group is the key to staying grounded. They are my bosses. I am accountable to them.” (Jack, Focus group 3)*

*“It is necessary to get additional roles that are outside the services as things are complicated when we are employees. We need ‘in’ roles too, but not just ‘in roles. There is a value to being ‘in’ that space. But, there’s a danger when we don’t have a variety of roles and a ’thicker’ workforce of say 8, 10, 15 people in the roles to cover all programs (Kate)*

## Leadership

Leadership was a complex theme that emerged from the data. While opportunities to develop consumer leadership were unanimously encouraged, the actual concept of leadership meant different things to different people. Participants also identified different sources of leadership - from DHS, from ‘good people’ working within mental health services and within the CWF.

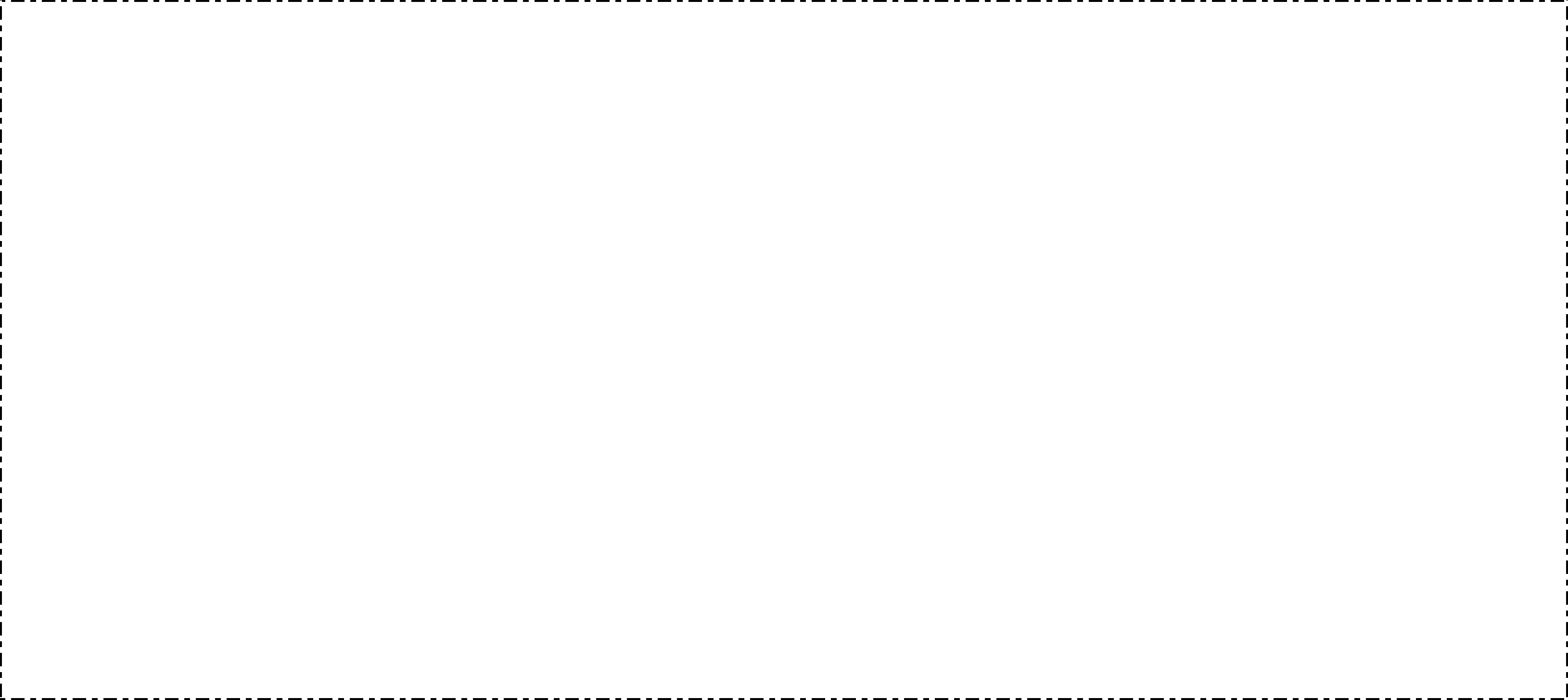
Strong leadership (or lack thereof) from the top was seen to be a critical factor in promoting the status & value of consumer work. It also determined whether the environment was supportive of good experiences for those in the CWF.



*“Consumer workers are needed at the Department of Human Services level. I’m critical that the DHS expects everywhere else to have consumer participation, but doesn’t have consumer participation job itself. DHS should be leading by example.” (Participant from Focus group 3)*

*They [the leaders] can be managers but they need to have very good empathy.” (Participant from Focus group 4)*

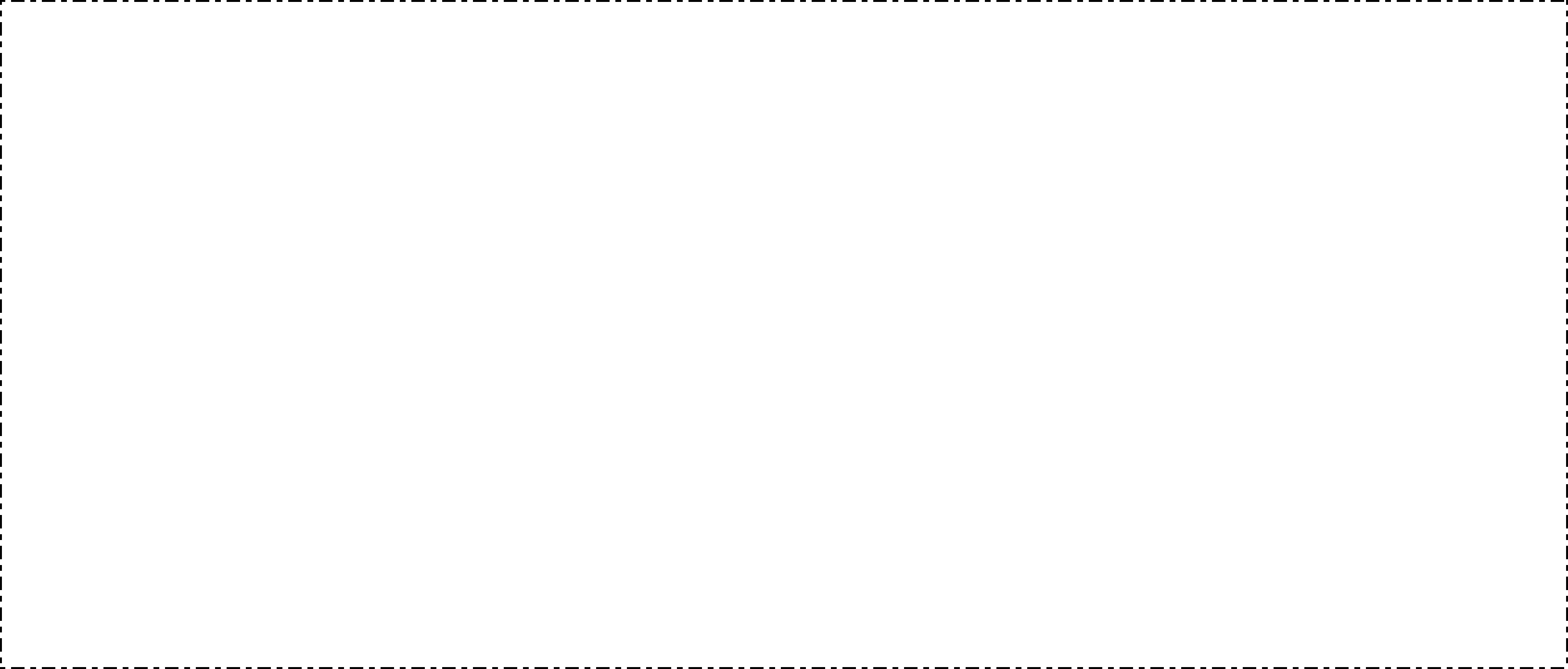
Leadership from DHS & mental health services was also critical to fostering leadership within the CWF, however participants pointed out that consumer notions of leadership often run counter to conventional ‘ways of working’ because they are not about hierarchy or control. This was considered a potential source of tension in terms of its impact on fostering leadership within the CWF. A level of caution permeated participants’ discussion on leadership:



*“It’s hard to talk about leadership if we’re not talking about the same things at a basic level. We are part of an oppressed group and oppressed groups have extreme mistrust of power and leadership is sometimes connected with meaning power over people. But, leadership can be different as well. It can be about capacity building and building strength in others, building up roles and grooming people into roles. I gravitate to this notion of leadership more naturally, but it is not a shared view. We are particularly mistrustful of power or things that are hierarchical and say – you’re better than me. This is how it seen by some and it is not helpful.” (Kate)*

*“I think it would be difficult for them not to become part of this hierarchy, but there might be a lot of advantages to having consumers in executive roles, management roles; interesting position.” (Arnold)*

Based on the participants’ discussion of this issue, it seemed that fostering leadership within the CWF was an important but delicate task that would require careful thought & planning. Cultural differences and limited existing support for the CWF were potential obstacles for acknowledging and promoting consumer leadership.



*“Consumer leadership needs to be acknowledged and one of the ways to open up opportunities is by opening up career structures through training, diverse positions such as specialist positions to build up expertise. We need opportunities to get out and explore, resourcing people in leadership positions to talk to others interstate and internationally” (Vicki)*

*“It would be good to have a social network for the consumer leaders – more informal discussions over coffee.” (Renee)*

*“I’m not convinced about this, but I’d like to see the potential for a consumer at DHS to be explored, but I think we need to think about it carefully. It would need to be partnership role, not a sole position. The DHS culture is different and I would be hesitant about going for a sole position.” (Vicki)*

# Discussion

The findings reflect the continuous evolution of the consumer workforce, and consumer workers’ energy directed towards its success. However, consumer workers in this study also conveyed a sense of frustration at the lack of infrastructure and resources to enable their work, and the challenges of fitting into a broader system that acknowledges the value of CWF in principle but not always in practice. This section discusses the major themes reported in the findings.

## The Essence of Consumer Work

Consumer workers in this study highly valued being employed in roles aimed at helping to improve the MH service system. Consumer perspective work is seen as a way to make consumer voices heard and to tackle stigma and discrimination in the community and in mental health services. Being part of the CWF is also about being part of a community of advocates and peers with diverse backgrounds, shared values and a shared mission. However, participants expressed frustration with the potential for effecting change in the face of a broad range of systemic barriers, observations of which are also reflected in the literature reviewed.

Many participants expressed disappointment at the slow pace of growth and development over the past twelve years. They suggested the need for catch-up planning and resources to adequately cover on-the-ground realities and to foster future growth in areas, such as education and training, research, peer support, mentoring and capacity building for consumer workers and consumer advisory groups (CAGs).

Further, the need to provide training for non-consumer mental health workers who manage, supervise or work with the CWF was raised as an important issue to address the gaps in understanding consumer perspective work within the sector. In addition to being underdeveloped in practice, this has been little discussed in the literature.

Recommendations:

* Support the continued growth of consumer consultant positions in all AMHS.
* Support the growth of other consumer workforce (CWF) roles including consumer advisory groups (CAGs).
* Expand CWF roles in education and training for the mental health workforce through staff training in area mental health services (AMHS), psychiatric disability rehabilitation and support services (PDRS), and within university education courses.
* Embed consumer perspective work in research, policy and peer support roles.
* Establish consumer leadership roles within DHS on all committees including consumer advisory and policy roles.
* Support the establishment of community roles to address stigma and discrimination in community services (such as Centrelink).

## The Dollars

The issue of funding impacted on many aspects of the work. At its core is the growth of consumer perspective work over the past decade, unmatched by proportionate growth in funding.

The need to resource a wider range of expanded roles, at various EFT levels was raised. The limited range of EFT positions, especially full-time work (1.0 EFT) often

forced consumers out of the CWF just as they started to understand the work or prevented them from taking this work on in the first place, thereby impacting on workforce growth. Additionally, the lack of full-time work disregards the fact that consumers have real lives that require financial stability.

Furthermore, participants conveyed a strong sense of responsibility towards the work that they were involved in; as well as the knowledge that if they did not do the work, the work would not be done. However, the time needed to maintain quality in consumer perspective work often exceeded paid hours. Working outside remunerated hours and away from office routines made it difficult for people in CC or other CWF roles to place boundaries around their work, leading to problems with the sustainability of roles, physical and mental health. Unclear parameters around consumer worker roles was seen by participants as unsustainable and counterproductive. Further, it creates a paradoxical situation - consumer workers working under difficult conditions to improve conditions for consumers accessing mental health services.

The lack of wage parity and variance in remuneration, as compared with other parts of the MH workforce, was also identified as a continuing problem by participants. In addition to breeding dissatisfaction and resentment, participants felt that this conveyed a strong negative message about the relative worth of the CWF within the mental health workforce. Nonetheless, the issue of pay structures was controversial amongst participants with little consensus about whether consumer workers should be paid according to experience or qualifications, an issue closely linked with the discussion around education and training (see below).

One other aspect of funding was related to consumer involvement in project budgets. Separate to remuneration, this issue was fundamentally about the ability to assert more control, influence decision making, and be involved in higher-level organisational planning.

More serious consideration of funding to the CWF would go a long way to demonstrating that consumer worker roles are a valid career choice and make an important contribution to the broader MH workforce.

Recommendations:

* Ensure that greater EFT is available to services, reflecting the size and demographics of each service.
* Encourage services to use equivalent full-time positions (EFT) as flexibly as possible, so as to create a range of positions including full-time positions as well as substantial part-time and casual positions.
* Enable consumer workers to negotiate full time and part time positions to suit their work/life balance as for any other employees.
* Fund CAGs separately to consumer consultants funding, to ensure adequate resourcing of both.
* Make adequate and equitable funding available to CAGs and casual CWF members to undertake professional development.
* Establish formal funding for the CWF in the PDRSS, youth and aged sectors.
* Ensure clear, open and transparent budgets for consumer work, and include discretionary funding to enable the CWF to respond to requests for additional input to time-limited projects, working groups and committees.
* Ensure fair representation of CWF in budgetary decision-making.
* Develop a process with consumer workers and representation from other key stakeholders to address pay and working conditions for the whole CWF.

## Pathways: Education, Training, Supervision and Mentoring

There was agreement regarding the present lack of opportunities and the importance of education and training for the CWF, as also noted in the literature. Participants viewed the CWF as best placed to drive, plan and deliver education and training applicable to consumer perspective work. Having support from non-consumers in the MH workforce was also considered necessary to enable the implementation of appropriate training. Critically, participants were unanimous that training needed to be affordable and accessible to all levels of the CWF.

The focus group discussions reflected the issue that education and training continues to be a contentious one for the CWF. The academic versus ‘lived experience’ question is an enduring debate in the CWF. Like other disciplines, consumer workers also debate the value of university-based courses versus the apprenticeship model or workplace-based learning, or indeed if there are other models to be explored. One of the major concerns is that an academic emphasis may exclude many people wishing to join the CWF. Further questions arise about the content and delivery of training programs consistent with CWF principles. It was also felt that developing both the content and approach of CWF training should reflect the diversity of consumer backgrounds, experiences and adult learning styles.

Consumer worker roles are demanding, complex and involve multi-tasking and diverse skills. There have been some notable attempts and ad hoc pockets of training to meet this need in recent years, but no formal training pathway open to people wanting to join the CWF. Structured education and training for any workforce is essential to the professional development of individuals and capacity building of the CWF. Participants felt that the lack of investment in this area pointed to a devaluing of the consumer workers.

The availability of supervision and support mechanisms for the CWF was also identified by participants as important to personal and professional development, yet often not recognised or supported within mental health services. Consumer worker supervision is often confused with line management, but is a specialised form of support that can come from a variety of people in the mental health sector. Mentoring

* formal and informal - is another form of support seen to be a strong contributing factor to CWF culture. Given the challenges of consumer perspective work, specifically making consumer voices heard, support is needed for problem solving, addressing conflicts, identifying learning needs, seeing the “bigger picture” and sharing new knowledge with others. Particularly many consumer roles are quite isolated across organisations, so that better structures are needed to ensure peer supervision, mentoring and networking. Management support for these structures is critical to sustain supervision and mentoring mechanisms for the CWF.

Integral to CWF education and evolution is building capacity to undertake research. Yet consumer perspective research is still relatively new and underdeveloped, which in itself impacts on the knowledge, skills and effectiveness of the CWF. It is therefore another area in need of further development.

Recommendations:

* + Establish a statewide working group of consumer workers with representation from other key stakeholders to scope and develop education and training for the CWF.
  + Develop a mentoring project pilot and trial within an AMHS and PDRSS.
  + Resource consumer-provided mentoring, support and supervision for all consumer workers, including the casual CWF.
  + Support a wide variety of people into consumer roles so that we are growing a larger and more diverse future CWF.
  + Establish pathways for consumers to develop a range of expertise in particular roles and areas.
  + Establish pathways geared towards preparing consumers for leadership positions.

## The Workplace

Participants identified the need for a supportive working environment to enable consumer workers to operate and achieve CWF goals. They shared many good examples of this being the case, but also reported experiences that were less positive and had compromised the quality of their work and working conditions. Both attitudinal factors and resources were prominent aspects of the workplace environment. As suggested by some CWF advocates, the persistence of attitudinal barriers and inadequate resourcing within the mental health service raises questions of tokenism in the effort to firmly implant consumer involvement in service delivery (Stewart et al., 2008).

Experiences shared in this study and the broader consumer literature highlight attitudinal barriers to consumer perspective work that lie within the MH workforce. While attributed to a variety of reasons, including systemic and bureaucratic pressures on services, these barriers continue to compromise consumer participation. These attitudinal barriers reflect a cultural divide between mental health services and consumer perspective work (Middleton et al., 2004; Watson, 2007), with practical implications as far as limiting opportunities for expansion of the roles and scope of the CWF, as well as a lack of resources, commitment and funding.

Under-resourcing, including lack of material resources, job descriptions and other practical considerations, were enduring problems for this group of consumer workers. While being resourced to do one’s job can be considered basic occupational health measures, participants reported the inadequacy of human resources, office space, and limited supplies of equipment and stationery necessary for consumer work. Participants felt that this reflected the pervasive attitudinal barriers resulting from poor understanding of CWF roles, or a lack of recognition or respect of consumer workers as ‘real’ staff. Little has been done to address this issue in a targeted way, and it continues to have a detrimental impact on the personal safety of CWF members and the work that could be achieved if support was in place.

The theme of personal safety raised by participants is echoed in the literature. Many Consumer Consultants and casual members of the CWF (such as CAG members) originally enter consumer perspective work because of experiencing or witnessing unsatisfactory treatment of consumers in the system. Paradoxically, the firsthand consumer perspective essential to the strength and validity of this work can also

become a major source of vulnerability for a CWF worker especially if support structures and job design flexibilities in the workplace are inadequate.

Consumer Consultants can become isolated, lose confidence and feel challenged by the complex web of knowledge, politics and stigma that exist in mental health organisations. Under some circumstances, consumer workers become captive to their own success. For example, success leads to new projects accumulating and workloads expanding. Sometimes it also raises tensions for consumer workers between being successful and perceived as ‘too challenging’ for services, or being ‘less challenging’ and therefore silenced, risking differential employment practices. The paradox here is that the CWF aims to advocate for safer places for consumers, yet the workplaces often compromise the personal safety of consumer workers.

Greater role clarity (eg, better defined job descriptions and responsibilities) may go some way to addressing the problem of consumer workers taking on too much, so that workloads are better regulated and overwork, burnout, and ill health are avoided. Advance Directives were also suggested as a way of preparing a better and self- directed path through possible times of illness.

More positive messages were provided by participants regarding what they find helpful in their workplace. These included being with other consumers to exchange ideas, mentoring or emotional support, promoting ideas that have worked well, and having flexibility in how one does one’s work. On an organisational level, the determining factors of success reflect the degree to which consumer workers are enabled to work in partnerships with service providers, mutual respect, and a genuine commitment to change and improvement within the mental health sector, based on consumer knowledge (Pinches, 2004).

Another component to a healthy work environment is one in which there is clear accountability to consumers from DHS, governance organisations, services and the CWF.

Recommendations

* + Promote healthy and safe workplace environments for the CWF by addressing the previously stated recommendations related to ‘The Dollars’ and ‘Pathways: Education, training, supervision and mentoring’. In particular, the importance of adequate consumer perspective supervision, peer support and consumer generated guidelines for this work cannot be overstated.
  + Support flexibility of working hours and arrangements.
  + Create access for Consumer Consultants and other consumer workers to administrative resources and support for tasks, such as computer work and photocopying, that can otherwise take away from time for specialist consumer work.
  + Provide regular opportunities for non-consumer staff to learn about the CWF, its roles as equal employees, and to experience the benefits of working with members of the CWF.
  + Implement consumer participation policies and services standards equally with other service policies and standards.
  + Ensure consumer perspective work is more closely embedded with health service governance including Community Advisory Committees (CACs). For example, Consumer Advisory Groups could be linked with CACs through some common membership.

## Leadership

The importance of strong leadership on all levels – consumer, organisational and DHS

* was identified by the study participants, although consumer leadership has yet to be grown or even acknowledged in most instances. Leadership within the consumer movement strives to come from ideals of peer support, respect for the lived experience of people in the system and in the community, and the belief that everyone has a story to tell and something of value to contribute. As such, fostering leadership in the CWF is likely to look different to traditional notions of leadership in mental health services. This will impact on how CWF leadership is perceived and recognised by services, but real participation and opportunities to influence change and decision- making will continue to fall short without it (Gordon, 2005). While participants identified that informally there are consumers who are named as leaders amongst their peers, and occasionally by others in the mental health sector, it is clear that this is an area in need of development – or as suggested by Happell and Roper (2006), “a movement to be led” (p.6).

Recommendations

* + Establish pathways to enable consumer workers to prepare for leadership positions.
  + Establish consumer leadership roles at DHS level on all committees including consumer advisory and policy roles.
  + Establish structures that create pathways for consumer workers to develop a range of expertise in particular roles and areas.

Conclusions

The findings of this study clearly highlight that consumer workers are doing ‘real jobs’ in the mental health sector that require real employment opportunities and working conditions. This underlines the need for improved organisational and job structures, supports, and strategic planning to sustain the consumer workforce.

Within the mental health sector, the consumer workforce has demonstrated its potential for bringing about positive change. A closer linkage of consumer participation activity to service management structures could help build stronger working partnerships, as well as challenging attitudinal barriers and misconceptions of consumer participation as an “add-on activity” rather than an integral part of service development and planning. Further, such moves are likely to bring about improved effectiveness and consistency of CWF job descriptions, develop more cohesive consumer participation work within services and the wider sector, and become more closely linked with planning and coordination of mental health services at DHS level.

This study provides insights into consumer workforce development in the mental health sector from the perspective of consumer workers. *Because mental health matters*, the Victorian Mental Health Reform Strategy 2009-19 (Department of Human Services, 2009), indicates an action plan to strengthen consumer participation is to be released. It also states that the development of consumer peer worker roles, expansion of the consumer consultant program across the different elements of MHS, support for consumers to play a more major role in the development of mental health research, and the potential of a collaborative centre to promote and support consumer-

led research and input into education, training and quality improvement are under consideration. In this context, there is an urgent need to address the consumer workforce issues identified in this study, so as to build a robust consumer workforce with the capacity for development and expansion in a sustainable manner.

Further research building on this study will also be necessary with the diversification of the CWF insofar as greater CALD and rural/regional representation is concerned, the expansion of consumer perspective work into relatively less developed areas, such as services for older adults, and the development of peer support programs.

Summary list of recommendations

### Essence of consumer work

* + Support the continued growth of consumer consultant positions in all AMHS.
  + Support the growth of other consumer workforce (CWF) roles including consumer advisory groups (CAGs).
  + Expand CWF roles in education and training for the mental health workforce through staff training in area mental health services (AMHS), psychiatric disability rehabilitation and support services (PDRS), and within university education courses.
  + Embed consumer perspective work in research, policy and peer support roles.
  + Establish consumer leadership roles within DHS on all committees including consumer advisory and policy roles.
  + Support the establishment of community roles to address stigma and discrimination in community services (such as Centrelink).

### The dollars

* + Ensure that greater EFT is available to services, reflecting the size and demographics of each service.
  + Encourage services to use equivalent full-time positions (EFT) as flexibly as possible, so as to create a range of positions including full-time positions as well as substantial part-time and casual positions.
  + Enable consumer workers to negotiate full time and part time positions to suit their work/life balance as for any other employees.
  + Fund CAGs separately to consumer consultants funding, to ensure adequate resourcing of both.
  + Make adequate and equitable funding available to CAGs and casual CWF members to undertake professional development.
  + Establish formal funding for the CWF in the PDRSS, youth and aged sectors.
  + Ensure clear, open and transparent budgets for consumer work, and include discretionary funding to enable the CWF to respond to requests for additional input to time-limited projects, working groups and committees.
  + Ensure fair representation of CWF in budgetary decision-making.
  + Develop a process with consumer workers and representation from other key stakeholders to address pay and working conditions for the whole CWF.

### Pathways: Education, Training, Supervision and Mentoring

* + Establish a statewide working group of consumer workers with representation from other key stakeholders to scope and develop education and training for the CWF.
  + Develop a mentoring project pilot and trial within an AMHS and PDRSS.
  + Resource consumer-provided mentoring, support and supervision for all consumer workers, including the casual CWF.
  + Support a wide variety of people into consumer roles so that we are growing a larger and more diverse future CWF.
  + Establish pathways for consumers to develop a range of expertise in particular roles and areas.
  + Establish pathways geared towards preparing consumers for leadership positions.

### The Workplace

* + Promote healthy and safe workplace environments for the CWF by addressing the previously stated recommendations related to ‘The Dollars’ and ‘Pathways: Education, training, supervision and mentoring’. In particular, the importance of adequate consumer perspective supervision, peer support and consumer generated guidelines for this work cannot be overstated.
  + Support flexibility of working hours and arrangements.
  + Create access for Consumer Consultants and other consumer workers to administrative resources and support for tasks, such as computer work and photocopying, that can otherwise take away from time for specialist consumer work.
  + Provide regular opportunities for non-consumer staff to learn about the CWF, its roles as equal employees, and to experience the benefits of working with members of the CWF.
  + Implement consumer participation policies and services standards equally with other service policies and standards.
  + Ensure consumer perspective work is more closely embedded with health service governance including Community Advisory Committees (CACs). For example, Consumer Advisory Groups could be linked with CACs through some common membership.

### Leadership

* + Establish pathways to enable consumer workers to prepare for leadership positions.
  + Establish consumer leadership roles at DHS level on all committees including consumer advisory and policy roles.
  + Establish structures that create pathways for consumer workers to develop a range of expertise in particular roles and areas.

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