Service-user perspectives on evidence: Shaping participatory mental health and homelessness services

Kate Davies

BACom, Griffith University, Australia
MPubPolMgt, Monash University, Australia

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University of Newcastle

School of Humanities and Social Science

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Statement of originality

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Conference presentations from this research


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Abstract

This qualitative study considered the potential for service-user participation and Evidence-based Practice (EBP) to contribute to socially just human services that aspire to improved parity of participation (Fraser, 2008a). A case study approach compared and contrasted the experiences and expectations of people who had used mental health services with those who had used homelessness services. The core data was derived from 11 interviews with mental health service users and 11 interviews with homelessness service users, with a sample of service providers (n=11) also interviewed to test for consistencies and tensions in perspectives. Key federal, state, and regional policy documents pertaining to mental health and homelessness were examined in order to compare policy intentions with the actual experiences of service users in relation to evidence and participation. Preliminary findings were presented back to small focus groups of service users (n=7) to test the accuracy and workability of findings.

This study was the first of its kind to examine the compatibility – or otherwise – of EBP and social justice. Literature reviews in the distinct areas of EBP and service-user participation revealed that, though deriving from quite different discourses, both concepts had been thinly conceptualised and poorly implemented in Australian human services. While ideal models of both EBP and participation existed, it was unclear that they had been translated into actual practice.

Respondents in both case studies reinforced the findings of the literature reviews that EBP was poorly understood and had failed to make an impression on the experiences of the most marginalised service users. While ‘consumer’ participation was prevalent within mental health policy and practice, it was just emerging in the homelessness sector and, in both the case studies the respondents revealed concerns about participation, given their broad and multifaceted identities, fluctuating capacities, and complex lives. Ultimately the study found that overly simplistic and inflexible models of EBP and participation were unsuitable for these service users and that a process, which emphasised the importance of relationship building between service users and service providers and which used the expertise and circumstances of individual service users as a lens through which to assess evidence, would contribute to
a model of EBP that suited the social justice frame. The positivistic ideology of EBP was at odds with the subjective notion of service-user expertise, but it was seen that both could contribute to improved accountability where EBP was conceived as a process and evidence was construed in pragmatic terms.
Social policy can be a minefield of technical jargon and political rhetoric, in which buzzwords mask the complexity and seriousness of the issues facing the people who use human and health services. ‘Client-centred’, ‘wrap-around services’, ‘no-wrong-door’, ‘bottom-up’, ‘outward-looking’, ‘social inclusion’, ‘partnership’, ‘participation’ and, of course ‘evidence-based’ are some of the terms to emerge in recent policy that have hinted at a promise of flexibility, responsiveness and accountability, but in reality, seem to have changed little at the coal face of service delivery. The concepts of Evidence-based Practice (EBP) and service-user participation have been ubiquitous in recent evolutions of social policy in Australia. This study sought to examine the extent to which the notions of EBP and participation have impacted on the experience of service use for some of the more marginalised and vulnerable users of human services in Australia. This thesis studied EBP from the service-user perspective, exploring the ways in which it might fulfil its promise of enhanced accountability, transparency and collaboration by realigning interventions with participatory social justice frameworks. It considers practice and policy making within the bounded frame of evidence-based and evidence-informed modes.

This study took the hypothetical claims of EBP regarding accountability and transparency and assessed them against the circumstances, preferences and experiences of people who had used services related to homelessness or mental health. It recognised that, despite apparent significant benefits, the failure for EBP to gain traction within human service policy and practice (Mullen, Shlonsky, Bledsoe, & Bellamy, 2005;
Murphy & McDonald, 2004) reflected a disjunct between the ideologies, processes and structures of human services and, more broadly, the social sciences, as well as the perceived ideologies, processes and structures inherent in an evidence-based approach. The study assumed that this disjunct related to EBP’s failure to take sufficient account of service-users’ knowledge and its lack of clarity on the service-user’s role. In exploring two case studies of homelessness and mental health service users, the study revealed that their experiences were highly variable, raising questions as to the workability of EBP and service-user participation within it. Users experienced human services as confusing, complicated, restrictive and authoritarian and reported a willingness to know more about and engage more fully in processes surrounding EBP. Had the opportunities been there, they would have participated in the hope of improving services to make them more relevant and accessible. The task then was to explore the potential for increased service-user participation and develop mechanisms to support service users in achieving what they considered to be successful outcomes. Finally, the study considered the implications for participatory modes of EBP that arose from examining human services through these service-user and social justice lenses, recognising the need for a more empirically sound understanding of the impacts of participation and process-oriented approaches that accommodate the complex and dynamic nature of individual service user’s capacities and circumstances.

**Background and rationale**

The impetus for this examination of participatory and evidence-based modes of human service policy making and practice came from the researcher’s professional experiences in policy and practice roles, where the consistent demands to implement interventions and programs were often detached from any real analysis or understanding of the effects
and impacts of those interventions. In crisis settings where service users have urgent unmet needs, the tendency to want to do something is often driven by genuine compassion and concern for the wellbeing of those people, but is also a politicised imperative to be seen to be responding. With an increasing emphasis on accountability within government and non-government sector human services, particularly outcomes-based performance measures in the wake of neoliberalism, the importance of positively changing people’s lives has been misinterpreted as the meeting of arbitrary performance targets that may or may not have meaning for the people using the services. As the literature reviews for this study (see Chapters 2 and 3) revealed, EBP and service-user participation strategies have been posited as mechanisms for achieving accountability to service users though they have derived from quite different ideological roots. As such, this research was an opportunity to step back from the pressures of implementing programs and interventions and to examine the ways in which frameworks and tools could be developed to shape the process of policy development and service delivery, and to reconnect accountable practice with the capacities, preferences and aspirations of service users themselves.

In 2009 the Research Institute for Social Inclusion and Wellbeing at the University of Newcastle received an Australian Research Council (ARC) grant to examine the implementation of EBP by Australian human service professionals. The project comprised a systematic review of empirical studies on EBP implementation, a survey of social workers through the Australian Association of Social Workers and a case study of a human services organisation attempting to implement EBP. Though this ARC-funded study provided valuable insight into the professional context for implementing accountable practice, what continued to be missing from the analysis, as with other explorations of EBP (see Chapter 2), was the service-users’ perspective. It
was considered that an in-depth qualitative exploration of service-users’ expectations, needs and demands would provide an important complement to the afore-mentioned ARC-funded study.

**Key concepts and assumptions**

The most fundamental assumption underpinning this study was that Australian human services were not adequately meeting the needs of the most marginalised service users and there was a need to improve the way in which human service policy is made and practice is shaped and delivered. This assumption was substantiated through the research because, from the service-user perspective at least, their experience of human service use was sometimes beneficial, always complex and often frustrating.

Another assumption underlying this study was that social justice in the form of participatory parity ought to be the goal for human services and social policy. The theoretical underpinnings of the study considered the impact of neoliberalism on social justice. Harvey (2007) explained neoliberalism as “a theory of political economic practices proposing that human well-being can best be advanced by the maximization of entrepreneurial freedoms within an institutional framework characterized by private property rights, individual liberty, unencumbered markets, and free trade” (p. 22). He was highly critical of the way in which neoliberalism had served to reinforce class structures and justify a reversal in redistribution such that more wealth flowed to a smaller proportion of wealthy people in the upper class and less flowed to those who had historically benefitted from state-based intervention. The inequality and disparity inherent in such a view of neoliberalism, whereby efficiency and economic rationalism have reigned supreme, suggest it has become questionable whether social policy and services have social justice as their ultimate aim. EBP has been appropriated to achieve
efficient, streamlined, outcome-driven practice and policy, and must now be reappropriated to achieve true structural change and genuine participation. Further, the concept of social justice tends to be an abstract one, often cited but rarely defined or conceptualised in a tangible sense. Nancy Fraser’s (2000, 2001, 2008a) principle of “parity of participation” proved invaluable in determining what social justice might look like within EBP and the elements contained within such a lofty aspiration. While this study critiques the mechanisms and strategies of participation, it does not seek to determine the actual impact and effectiveness of the service-user participation movement, although there is a recognised need for more empirical studies to identify the actual impact of service-user participation (Carr 2004, 2007). Rather, it identifies the types of participation frameworks that might contribute to more accountable and collaborative practice and policy making and analyses these frameworks in relation to the actual experiences and aspirations of service users. It is an acknowledged limitation of the study that it does not seek to measure or clarify the success or otherwise of the service-user participation movement.

A complicating factor for any analysis of Australian human services is the blurred boundary between various service sectors, particularly between health and community services, but also justice, education and employment. While specific issues or population groups may be funded and supported primarily through one agency, the needs of individuals experiencing a specific issue or belonging to a population group are likely to bring them into contact with a mix of government and non-government agencies across a range of sectors. For example, while mental health services and interventions are funded primarily through health sector agencies, they are often delivered in community-based settings. A person with experience of mental illness may use formal health services, such as clinics and hospitals, as well as a range of allied
health services when they are acutely ill, and they might also be receiving benefits from Centrelink, another government agency, as well as housing services. Family and social support, however, would most likely come from non-government agencies. Those who can afford their services might use private therapy providers and care services. As the respondents in this study attested, the distinctions between the various sectors were unimportant to the service users themselves, but often served as complicating and restricting barriers for accessing services and funding. At federal and state levels, government agencies have unsuccessfully attempted greater interagency collaboration to make the division of responsibilities less problematic and service use more streamlined (Australian Government, 2008a, 2012). The distinction between sectors is further complicated by the different levels of government in Australia and the diverse ways in which agencies are defined at each level and in each state and territory. For example, the federal government develops policy and allocates funding but rarely implements services directly. At this level, human services fit most neatly within the Department of Families, Housing, Community Services and Indigenous Affairs (2011). Broad priority groups served by this department include families and children, public housing clients, homeless people, Indigenous Australians, mental health service users, people with disability, seniors, and women. The federal Department of Human Services (2012) within the Finance and Administration portfolio has primary responsibility for health, social and welfare payments and programs delivered through Centrelink, Medicare and child support. The federal Department of Health and Ageing has responsibilities for people with mental illness and disability and seniors. In New South Wales (NSW) where this study was conducted, human service responsibilities generally fall under the state Department of Family and Community Services, while similar functions in Victoria are located in the Department of Human Services. Many non-government
agencies deliver services funded through diverse means, including government grants, philanthropic and fee-for-service arrangements. They often receive funds from sources that cover a range of sectors. For example, a non-government agency may be under government contract to provide employment services while at the same time providing emergency relief funded from private donations. The indistinct definition of what constitutes the human services within Australian policy made the services discussed in this study as broad and diverse as the service users interviewed deemed appropriate and relevant. The fact that service users cut across various service sectors added depth to this analysis of participatory EBP. However, it should be noted that, despite its ambiguity, the term ‘human services’ has been retained as a feature of the study primarily to distinguish between EBP as it pertains to social sciences – more relevant to human services – and evidence-based medicine as it pertains to medical interventions and treatments. Evidence-based medicine is considered a related, but different tool, and so while experiences with medical services are referred to as important aspects of the spectrum of service use, they are not the focus of this study and human services and social sciences are considered distinct from these medical models. The term ‘social services’ could be used interchangeably for the purposes of this study, although ‘human services’ and ‘community services’ are the more common terms used in Australia.

In discussing their experiences of service use, respondents in this study frequently referred to “the system”, by which they meant the web of human, health, justice, welfare and other services delivered by government and non-government agencies. However, the term ‘the system’ also hinted at respondents’ recognition that the services they used (or delivered) reflected deep, systemic cultural and political values and social and economic priorities. By framing this study within the lens of social justice, and more specifically parity of participation, the term ‘the system’ was
imbued with the characteristics of inequity, disparity and subordination of marginalised groups and individuals, or, alternatively, represented efforts to improve or overcome this disparity. That is, the system was not seen as an objective, neutral network of services, but as the manifestation of the ideologies and values that shaped the way policy was devised, resources allocated and services delivered. The case study approach was very useful in examining the relationship between the system and participatory EBP, because the histories and ideologies that shaped the homelessness and mental health systems were quite different.

As is discussed further in Chapter 3, the terminology for describing the people who use, or are the target beneficiaries of, human services is contested and unresolved. While the term ‘consumer’ has gained prominence within much of the policy and literature pertaining to participation in Australian human services, and was a term commonly used by the respondents in this study to describe themselves, it has not been used in this study except where the analysis pertains to a body of literature or data that has specifically used the term ‘consumer’. The term ‘consumer’ has deliberately not been used because it closely aligns with neoliberal conceptions of service use, whereby the consumer knowingly selects the services they wish to access and exerts market power, a conception which this study sought to question. The study sought to examine the extent to which this type of market power participation was a feature of service use and, therefore, the way in which the notion of the service user as consumer might or might not feature in practice and policy making that was evidence-based and participatory. As such the term ‘service user’ has been used despite the fact that it suggests a degree of passivity on the part of the individual and prioritises the service as the frame of reference rather than the individual. In this instance, because the study examined people’s use of a particular range of services and because there has, as yet,
been little agreement on a preferred term, it was deemed appropriate to use the term ‘service user’.

In describing the value of the knowledge that came from experiencing either homelessness or mental illness and of accessing the various support services available, respondents frequently used the term ‘lived experience’. Deriving from anthropological research approaches in which the stories of the subjects form the knowledge (Turner & Bruner, 1986), the concept of gleaning and valuing lived experience of research subjects has become a recognised tool within qualitative research (Padgett, 2008). However, the term has become ubiquitous in mental health literature and linked to the notion of recovery, whereby the lived experience of people shapes their aspirations and strategies for managing their mental health (Fisher & Happell, 2009; Gould, 2006). In this study respondents talked about the way in which their lived experience had been valued or disregarded, and the impacts for models of EBP. Thus, in this study lived experience was used as a methodological tool to gather data directly from the people who had experienced mental illness or homelessness and used the various services available, and also as a concept that emerged directly from service users themselves to describe the knowledge that came from experience and which was then explored in relation to concepts of evidence and expertise.

**Methodology**

The methodological approach recognised that there was little known about Australian service-users’ involvement in human service provision or service-users’ perspectives, including their knowledge and awareness, of EBP. As such, the research was a starting point for identifying options for service-user involvement at the early stage of EBP’s development to ensure that service users were an important part of implementation from
the outset. Literature reviews in the distinct areas of EBP and service-user participation established that there was little consistency in understandings of either concept within the social sciences and that there was a dearth of research exploring connections between evidence and participation. The case study approach provided a means to track from policy, examining the intentions and priorities of current Australian policy, to lived experience, examining the ways in which service users valued and engaged with evidence and participated at individual and representative levels in shaping services. Two case studies were purposefully selected to compare and contrast the mental health sector, in which participation and EBP were more entrenched, with the homelessness sector where approaches to EBP and service-user participation were in the early stages of development. Within each case study, key federal, state and regional policy documents were analysed to understand the context for EBP and participatory strategies for service-user involvement. The key source of data, however, was the in-depth interviews with 11 homelessness service users, 11 mental health service users and a sample of service providers in order to establish consistencies and/or tensions between service users’ and providers’ understandings. Preliminary findings were presented to small focus groups of service users to test their relevance and validity and to explore their implications.

**Theoretical framework**

The theoretical framework built on the assumption that social justice ought to be the principle goal for human service policy and practice, and as such, EBP needed to disengage from neoliberal ideologies and connect with strategies to support participation and equity in service provision. This was an idea endorsed by a number of EBP critics who suggested that a positivistic focus on “what works” had been
appropriated by new public management, so EBP was being used as a tool for outcome measurement rather than its true purpose of social service improvement (Dore, 2006; Hammersley, 2005). Interestingly, prominent supporters were those who saw it as a bottom-up process that was responsive to the preferences of clients and the wisdom of practitioners (Gambrill, 2006a, 2006b; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). It seemed, from preliminary reviews of the literature and key debates on EBP, that the ability to advocate eloquently for its place in the social sciences depended largely on the ability to reconcile its values with those such as client-centredness, responsiveness and participation. As such, Gambrill’s (2006b) ideal-type construction of EBP as a bottom-up, client-centred process was integral to the formulation of a theoretical framework for this study, because it demonstrated, conceptually at least, the qualities that would be important for EBP to emphasise in order to align with social justice aspirations. These included collaboration, shared knowledge, transparency, service-user choice and accountability.

To examine the positivistic domain of EBP in relationship to the highly subjective and often intangible domain of participation required a conceptualisation of social justice that would serve as a heuristic device and a standard by which to analyse the claims of policy and the experiences and expectations of service users. Fraser’s (2000, 2001, 2008) notion of parity of participation provided such a theoretical framework to consider the appropriateness of EBP to the social justice agenda. She claimed that the ultimate test of social policy was whether it enhanced or detracted from a subordinated individual’s opportunity to participate in the full spectrum of social activity, extrapolating three domains by which disparity in participation could be redressed: redistribution (economic), recognition (identity) and representation (political). For the purposes of this study, the framework of participatory parity
provided a challenging and insightful lens through which to examine the homelessness and mental health case studies. It was challenging because it required a reinterpretation of vague and often ineffective conceptualisations of participation that dominated much social policy and highlighted the problems for enacting the type of bottom-up approach advocated by commentators such as Gambrill (2006b). It was insightful because the service-user perspectives revealed through the case studies consistently iterated the complex and multifaceted nature of their crises, capacities and aspirations. By considering these different stories against the backdrop parity of participation, their place in structural reform became clearer.

**Significance of the study**

Mullen et al. (2005) suggested that definitions and understandings of evidence are dynamic and ought to evolve in line with changes in values, methodologies and ethics. Pawson et al. (2003), in assessing and categorising the types of knowledge relevant to social care, described a “complex world of latent, emerging and actual standards that might be applied to knowledge” emphasising the importance of continually applying and refining models of knowledge to improve “the robustness of standards and their intelligibility, practicality and acceptability to a wide range of social care knowledge users” (p. 68). In order to fulfil its mandate of improved accountability, transparency and quality, EBP needs a reconfigured approach within human service policy and practice, a significant component of which is an improved understanding of the relationship between service-user derived forms of knowledge and empirically derived evidence. This study offers a unique contribution to the dynamic challenge described by Mullen et al. (2005) and Pawson et al. (2003) in making the service-user perspective central to the judgement about what should be considered evidence. This study takes the
concerns and criticisms regarding EBP, in terms of its inappropriateness to social sciences, and examines a possible way forward that embraces the best of EBP and the ethical social justice underpinnings of the human service sector. The study translates the rhetoric of notions such as client-centredness into strategies for devising policy and delivering services that reflect the real-life circumstances and aspirations of service users.

While providing a unique insight into the realities, complexities, challenges and benefits of EBP within the homelessness and mental health service sectors, it also critiques and confronts the weaknesses in participation theories and strategies that have had mixed impacts on effecting structural change for marginalised groups and individuals. By considering participation as a process or strategy (as in service-user involvement), and as an ideal reference point or benchmark (as in parity of participation) in relation to EBP, the study reveals pronounced gaps in claims regarding the benefits of existing participatory practices and highlights the dangers in adopting one-size-fits-all models to highly diverse and complex groups of individuals.

The study has been designed to offer a unique contribution to theoretical debate regarding EBP and participation, and to draw out insights and implications relevant to service users, policy makers and service providers at the coal face. Findings from the study were presented to service provider and service-user groups in the areas of homelessness and mental health as a reference to inform their development of evidence-based and participatory strategies.

**Overview**

Given the distinct fields from which EBP and participation derive, and the fact that this study is premised on the assumption that neither has been well developed nor utilised to
further the agendas of marginalised service users, literature reviews on each field act as a starting point for the thesis. The literature reviews at Chapters 2 and 3 explore the contested meanings of evidence and participation, key current debates, Australian-specific iterations and existing bodies of literature where evidence and participation interrelate. Relevant ideas from each of the literature reviews are then compiled within a theoretical framework that hypothesises the potential interactions between EBP and participation. Chapter 4 describes the methodological approach for assessing this hypothesis in detail, with particular emphasis on the benefits and limitations of a qualitative case study approach. The case studies are presented in Chapter 5 (Homelessness) and Chapter 6 (Mental Health), describing the policy context for each study and summarising key data collected through qualitative interviews and focus groups. The data from the two case studies are compared and contrasted in Chapter 7, and key conclusions are drawn in Chapter 8, with an examination of the implications of these conclusions for policy making, practice and service use.
CHAPTER 2

Evidence-based Practice Literature Review

This chapter explores the literature that exemplifies the varying and often conflicting meanings and models of EBP. The focus is on literature that applies to social science and welfare settings, but in order to gain a full understanding of the challenges and opportunities inherent in EBP, key works from medical and scientific fields are also considered. The review draws out the ways in which influential thinkers have conceptualised the role of the service user in EBP. It considers the ways in which EBP may be seen as a tool to promote and enhance the active participation and wellbeing of service users or, alternatively, as a restrictive and problematic mechanism which could exacerbate power inequalities and fail to value individual contexts and complexities. In considering the EBP literature from a service user and social justice lens, questions will be raised concerning the nature of evidence and its relationship to goals regarding economic, cultural and political participation.

The aim of the literature search (described at Chapter 4) was to locate material which considered EBP within the human or social services or welfare context more broadly. However, much work on EBP within the social sciences derived from the medical sciences, and these were included to provide an overview of key definitions and influential authoritative sources.

EBP is posited as a means to achieving client-focused service delivery and meeting ethical and professional accountabilities to clients (Chalmers, 2005; Gambrill, 2006b; Thyer, 2008). However, despite perceived potential for EBP to improve outcomes for clients, its implementation within social services has been limited
(Mullen, Bledsoe, & Bellamy, 2007). Within the medical sciences, where EBP originated, there has been debate about the concept of evidence and its relationship with professional wisdom and qualitatively generated modes of evidence (Chalmers, 2005; Sackett, et al., 1996; Williams & Garner, 2002). EBP has been even more controversial when applied to the social sciences and has sat uneasily with the egalitarian aspirations of social services and policy.

The definition of EBP varied across the literature, with terms such as evidence-informed practice, evidence-aware practice, research-based practice, knowledge-based practice, and evidence-based practice and policy used in various ways to express subtle differences in the type of process and notion of evidence described. Critics and supporters debating the perceived value, or otherwise, of EBP often described very different models of EBP, to the extent that they did not directly disagree. Generally, the issue was about different interpretations of the meaning. In fact, the literature review did not reveal any instance of an argument that evidence should not inform practice and policy to some extent or that evidence was not an important tool in decision making and policy making. The arguments were essentially about the form that practice should take to utilise evidence effectively, the value and relevance of the hierarchy of evidence, and the relative importance of factors such as professional wisdom and service-user input.

The literature review revealed that EBP had yet to meet its perceived potential in the human services. The role of the service user was only beginning to be analysed and theorised and significant gaps remained in the understanding of how EBP could be formulated and used in a way that met the goals and values of social services, including participatory approaches.
Evidence-based practice: Definitions and debates

As its roots are based in medicine, EBP’s fundamental concepts were derived from work relating to evidence-based medicine. The most commonly cited definition came from Sackett et al. (2000). Their original definition (Sackett, et al., 1996) described a process that involved the:

… conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research (p. 71).

Their definition proved fundamental to the current debate within the social sciences because it laid out some of the key characteristics of the model promoted by many EBP supporters. First, this definition indicated that (in and of itself) evidence did not give the answers but that it must be considered and applied appropriately. There was an equal emphasis placed on professional expertise. Secondly, the description of the current best evidence included a range of evidence types, not restricted to randomised controlled trials, although Sackett et al. (1996, 2000) did indicate that research should be systematic. They considered best evidence as that which was most applicable to a particular client situation. Thirdly, their description of EBP was very much a client-focused model in which the clinician’s search for, and analysis of, evidence was driven by the individual client’s situation, values, preferences, and interests. They explicitly stated that EBP was not, nor should it be used as, a “cookbook” (p. 72) approach to practice or an authoritative model. Despite this oft-cited definition of EBP and its formative contribution to current understanding, fears about the value of EBP continue ad infinitum.
Chalmers (1995, 2005) was a key contributor to the early debates. His work traversed the fields of the medical and social sciences. His approach to EBP asserted clearly that the judicious use of evidence was a professional responsibility, suggesting that failure to apply rigorous, scientific evidence to decision-making practices was potentially detrimental to the wellbeing of clients. Randomised controlled trials were posited as an important tool for reducing bias and providing reliable evidence in evidence-based medicine. Chalmers’ (2005) promotion of EBP was motivated by examples of significant harm caused by clinical interventions and practices that were not sufficiently supported by empirical study and hard evidence. His perspective was important to the present study because he attempted to put himself in the position of clients or service users to consider their expectations regarding professional knowledge and decision-making processes, even though there had been no studies to suggest that his interpretation of client expectations and needs regarding evidence was accurate (Chalmers, 1995). This was what this study sought to address. Interestingly, Chalmers (2005) promoted a model, which he called “evidence-informed policy and practice” (p. 230) in recognition that research evidence alone would not lead to good decision making.

Hammersley (2005) was Chalmers’ most vocal critic. Hammersley (2005) argued that the EBP movement was fraught with risk since it took the emphasis away from professional judgement. He also suggested that what Chalmers perceived as “bias” and “uncritical practice” (p. 89) was actually indicative of bad practice and a failure on the part of the practitioner which would not be aided by EBP. The Hammersley-Chalmers debate was representative of much of the literature. Though one was posited as a supporter of EBP and the other a critic, both argued for the importance of high quality, rigorous research evidence to support clinical practice interventions. Both
agreed that professional judgement was pivotal: that clinical practice turned on the way
in which evidence was critically analysed, applied, and used by professional clinicians
or experts. The fear that EBP did not sufficiently account for professional judgement
and practice wisdom was a recurring theme in the critical literature (Dore, 2006; Williams & Garner, 2002).

Hammersley (2001) was highly critical of the systematic review process. He
claimed that this process incorrectly assumed that the purpose of research was the
determination of “what works best” (p. 544). Here too he highlighted the importance of
professional judgement and suggested that the systematic review process did not
adequately consider the centrality of professional judgement in the assessment of the
client’s or patient’s problem. The emphasis on what works best implicit in the
systematic review process was seen to offer limited insight regarding context and
judgement. These concerns emanating from evidence-based medicine were also
reflected in the literature regarding EBP in the social sciences, whereby the nature of
knowledge and the role of research were continually brought into question.

Trinder (2000) placed the supporters of EBP within the social sciences in two
camps: empiricists and pragmatists. She believed that empiricists promoted a model
more closely related to evidence-based medicine which relied on the evidence hierarchy
and experimental research designs to determine what works. In contrast, pragmatists
advocated a looser definition of evidence, looking towards a more general model that
improved the relationship between research and practice or policy making. In her
analysis of social work and probation services in the United Kingdom, Trinder’s (2000)
finding was that neither version had become dominant. Instead, she found that a
managerial emphasis was emerging. She urged that less effort should be expended on
arguing about definitions of evidence and more attention should be focused on the
research and effectiveness agenda that had emerged from the EBP debate. The most valuable consequences of the debate were that it highlighted the importance of research to practice and policy making and it increased the general call for practitioner and agency accountability.

The distinction between pragmatic and empirical definitions of EBP were explicated further by Plath (2008) who suggested the theoretical influences of positivism, pragmatism, politics and postmodernism had shaped diverse approaches. The positivist approach was seen to favour gold standard evidence as per the hierarchy of evidence and considered that research ought to direct practice. In contrast, pragmatists prioritised the usefulness and relevance of evidence and perceived a “symbiotic relationship between research and practice” (Gray, Plath & Webb, 2009, p. 53), while the political interpretation focused on the strategic usefulness of evidence and evidence as a tool for lobbying and advocacy. Postmodernism was considered to have shaped a perception of evidence as discourse that could contribute to interpretations and understandings of the meanings of experiences and the roles of professionals. Trinder’s (2000) and Platth’s (2008) analyses of the various and often conflicting schools of thought regarding EBP were significant to the debate about its applicability to complex human service settings. These theoretical influences represented the foundations for the varied interpretations of EBP that existed in the literature and also in practice settings. Support for EBP was likely to depend largely on the interpretation and understanding.

Advocates of EBP within the social sciences were those who were able to reconcile the approach with notions of client rights, and empowered or informed decision and policy-making processes. Within this understanding, practitioners were seen to “have a fiduciary duty to acquire the knowledge required to answer the question ‘What do you recommend?’ based on the best available scientific information” (Roberts
& Yeager, 2004, p. 3). There was a perceived ethical responsibility to provide treatment supported by empirical evidence and to make this evidence available to service users. Further, there were even suggestions that there might be an emerging legal right for clients to have access to EBP (Myers & Thyer, 1997).

EBP was seen as part of the practitioner’s commitment and accountability to the client. Gambrill (2006a, 2006b) was a strong proponent of EBP, within social work because she conceptualised it as a client-centred process. She acknowledged the struggle to define EBP that had taken place, asserting that, by prioritising ethics, it was clear that a model that was broad in its definition and not a guideline approach was most suited to social work. This process was seen to reduce authoritarian decision making and to promote transparency by being open with the client about the gaps and limitations in evidence.

Shlonsky and Gibbs (2006) supported a similar process-oriented notion, claiming that concern around its potential to be a top-down, guideline approach was unwarranted. Like Gambrill, they viewed EBP as a bottom-up process that began and ended with the client. For them, proper consideration of client values and preferences and professional expertise should be applied in conjunction with the practitioner’s understanding and interpretation of best available evidence.

These descriptions of EBP as a process focused on its capabilities as a tool for individual client treatment, particularly in social work settings. Pollio (2006) referred to the “art” (p. 242) of EBP as the process of translating evidence into each unique client-system relationship and interaction, although he was critical of the poorly conceptualised approach to training. This type of treatment-level process was one that viewed EBP as an empowering tool for clients and as a professional requirement of practitioners (Hope, 2002).
In contrast, critics saw EBP as destructive to the very “essence of social work” (Dore, 2006, p. 232) and noted its failure to encapsulate the complexities and multifaceted nature of social service practice. The types of decision-making processes suggested by Gambrill (2006b) and other advocates implied that there was a level of rationality on the part of the client who would engage in a logical, problem-solving analysis whereby they would weigh up the options and draw on the available evidence and expertise of the practitioner. Luitgarder (2007) claimed this rational choice model was at odds with the intuitive nature of social work. Further, he cynically suggested that EBP had been adopted in the United States in particular, for its potential to avert legal risk and to minimise the risk implicit in decision-making processes.

In short, there was a recognised tension between the pragmatic view of EBP that encompassed the incorporation of client values and professional expertise in Sackett et al.’s (2000) later definition of evidence-based medicine and the hierarchy of evidence which they posited as a defining feature of their earlier model (Sackett et al., 1996). Hence a great deal of cynicism as to its applicability to the social work and human services field continued.

**The nature of evidence**

The hierarchy of evidence was the source of much conflict in the understanding of EBP within the human services because it was seen as a rigid, didactic framework that contradicted the client-centred process presented by advocates of evidence-based human services.
A multitude of interpretations of the hierarchy of evidence abound. M. W. Fraser et al.’s (2009) perspective is illustrated in Figure 2.1. By way of contrast, Rosenthal (2004, p. 23) presented the hierarchy as follows:

1. Systematic reviews or meta-analyses of multiple, well-designed controlled studies
2. Well-designed individual experimental studies (randomised, controlled)
3. Well-designed quasiexperimental studies (nonrandomised, controlled)
4. Well-designed nonexperimental studies (nonrandomised, uncontrolled)
5. Case series and clinical examples, expert committee reports with critical appraisal
6. Opinions of respected authorities, based on clinical experience.
One of the most notable differences between these two interpretations of relevance to this study was the absence of consumer opinion in the second model. However, consumers might be included in the category of “respected authorities”.

The highest level of the hierarchy, that of meta-analyses or systematic reviews of randomised, controlled trial or experimental studies was often referred to as the “gold standard” of evidence (Boaz, Ashby & Young, 2002, p. 7; Gray et al., 2009, p. 4; Gueron, 2007, p. 134; Soydan, 2008, p. 315). Exponents of the hierarchy argued that “gold standard evidence” was likely to be less biased and present a more accurate analysis of effective interventions than methods further down the hierarchy (Boruch, 2008; Roberts & Yeager, 2004). The hierarchy of evidence was seen as a means for maintaining scientific rigour, given the high quantity, low quality nature of much research-generated evidence. It has featured more prominently in debates about evidence-based medicine where clinical trials on large cohorts were necessary and thus used more widely to generate evidence than in the social and human sciences. However, the hierarchical analysis and classification of evidence is a scientific and systematic function, quite separate from the process of implementing EBP, even in evidence-based medicine (Sackett et al., 1996, 2000). Implementing EBP involves scientifically unrelated issues, such as service users’ values and preferences and practitioner expertise. Hence it is a collaborative process involving service users and professionals as well as other key stakeholders.

The appropriateness and feasibility of randomised controlled trials in the social sciences was a controversial issue and one that perhaps sat at the heart of the EBP debate in this field. While the benefits of EBP were much discussed, the uptake in the social services was slow (Moseley & Tierney, 2005; Mullen et al., 2007; Murphy & McDonald, 2004). This might be attributable partly to the flaws in the definition and
understanding of evidence and challenges of a hierarchy that prioritised randomised controlled trials (Mullen et al., 2005). Mullen et al. (2005) asserted that the problem was not just about valuing quantitative over qualitative evidence, but also related to a dearth of hard evidence in the social sciences, and the challenges for efficacy as opposed to effectiveness testing. By their very nature, randomised controlled trials were strictly controlled environments that might fail to account for real-world complexities and to properly contextualise research. There was a sense that what worked in experimental or laboratory settings was not always relevant to real-life, individual situations.

Not all supporters of EBP in the social sciences necessarily supported the rigid hierarchy of evidence or advocated randomised controlled trials as the gold standard. However, some of the literature showed the potential and possibilities for randomised controlled trials within the social sciences. For example, Gueron (2007) described her involvement in randomised controlled trials within public welfare programs in the United States. She demonstrated that, while costly, difficult to administer, and ethically controversial, this type of experimental research had provided systematic, descriptive data that had helped to debunk certain misconceptions about welfare programs. She was clear that this type of research was not intended as an advocacy tool, that it must report negative and positive findings and that, although the data might be rich and informative, it was nevertheless prone to politics and might not have the expected influence on policy.

Boruch (2008) saw the advent of EBP in the social sciences as a valuable opportunity for randomised controlled trials, given their ability to reduce bias. He described the ethical considerations that came into play, in the United States. Randomised controlled trials tended to be perceived as justifiable only where the social problem was serious, where potential solutions were debated, where the results would
be more credible than those produced by other methods, when results were likely to be applied, and when assurance could be given that human rights would be protected.

A more measured and cynical approach was expressed by Berk (2005), who presented an overview of the benefits and challenges of randomised controlled trials, noting that “if the truth be told, there is no gold standard” (p. 431). He believed that, while there were issues with causal inference, they were significantly less worrisome than those with other methodologies, such as observational studies and that, when used with due caution and despite their imperfections, randomised controlled trials were one of the best available tools for reliable empirical practice.

Oakley (2006) was one of the most visible and targeted supporters of scientific evaluation tools within the social science EBP model, particularly in the field of education. She was highly critical of resistance to empirical technologies such as randomised controlled trials. She viewed this as indicative of a more general resistance by academics to new technologies and an indication that many within education, in the United Kingdom in particular, were not willing to accept the criticisms of the state of education that such methods revealed. Ultimately, hers was an appeal for the social sciences to come to terms with their “science” (Oakley, 2006, p. 78) and to adopt an open approach to using technologies that might yield more accurate and insightful results than currently used methods.

One of the most fundamental criticisms of the hierarchy of evidence was that it excluded or undervalued important evidence derived from sources such as practitioner expertise and qualitative research methods. Fraser et al. (2009) proposed an interesting reconceptualisation of the hierarchy of evidence asserting that it was more effective to invert the hierarchy when undertaking intervention research. Under this model, the first step was to seek the opinions of practitioners, consumers, and experts to develop
intervention content. The intervention was then formulated and qualitative and quantitative testing measures were applied as the intervention was further refined. The randomised controlled trial would only be undertaken on a fully developed intervention program. As such, it was a process of testing en route to the tip of the hierarchy which acknowledged that each level of evidence could offer a valuable contribution to building the knowledge base about a specific intervention.

Denzin (2009) called for staunch resistance to the notion of a single gold standard evidence type, viewing this hierarchy as a realisation of Habermas’ prediction that human rights and democracy would be compromised through moves towards empiricism and positivism. He saw the hierarchy of evidence as a threat to the inquiring nature of social science research that disregarded the political, ethical, and complex nature of the phenomena studied in the social field. This was perhaps at the heart of the failure of EBP to resonate with the social sciences.

Pawson (2006) questioned the value of systematic reviews, highlighting the potential risk that the process could misconstrue research, fail to provide the kinds of information needed, and miss valuable sources of evidence. Systematic reviews, as per Hammersley’s (2001) critique, did not sufficiently consider the context in which interventions operated and, by focusing on the issue of “what works”, they were fundamentally misleading. What was more important, he asserted, was how, why and in what circumstances an intervention or program worked. A program might be seen only to be proven successful in the exact conditions and environment in which the evaluation took place. Instead, what was valuable for those designing policy and programs was to look at the contextualised components that contributed to successful outcomes. He recommended a realist synthesis approach, which considered contextual layers, such as the capacities of individual key actors, interpersonal relationships supporting the
intervention, the institutional setting, and the wider infrastructural system. He also emphasised the importance of qualitative knowledge and research. His approach has had some resonance with Australian researchers. Recent work produced by the Australian Housing and Urban Research Institute (AHURI) adopted the realist synthesis approach to identify factors for success in programs to address homelessness (Gronda, 2009).

The value of qualitative research and its unresolved place in EBP were issues being taken up by the Cochrane Collaboration, the major body responsible for the production of systematic reviews in the health field. The Cochrane Collaboration established a Qualitative Research Methods Group, which recognised that “Qualitative research can help us to understand the way in which an intervention is experienced by all of those involved in developing, delivering and receiving interventions, what aspects of the intervention they value, or not, and why” (Cochrane Collaboration, 2002, The Focus of the Qualitative Methods Group section, para. 2). As such, it could be seen that, even in the field of evidence-based medicine where it was often perceived that the hierarchy of evidence more strictly applied, there was an acknowledgement of weaknesses in the current model. The low value placed on qualitative research within the hierarchy of evidence suggested that it was not as rigorous and credible as quantitative research and there were significant challenges for the Cochrane Collaboration to effectively incorporate qualitative findings into their work. Daly et al. (2007) devised a qualitative research hierarchy in response to this challenge (see Figure 2.2). They attempted to set criteria by which qualitative evidence could be classified as rigorous and relevant so as to ensure its application with EBP and evidence-based policy-making processes. Their focus was on generalisability as an indication of rigour, although it is questionable as to whether in reverting to a hierarchy they have misjudged the real value of qualitative study, in that it is able to reveal the intricacies and
contextual specificities of group or individual circumstances. However, Daly et al.’s (2007) attempts at ranking qualitative research signified a key concern regarding EBP in the social sciences, because qualitative research methods were especially popular and were considered by many to be a crucial means of examining the complex and personal experiences of service users (Baxter, Thorne & Mitchell, 2001; Boaz, Ashby & Young, 2002; Denzin, 2009; Glasby & Beresford, 2006). Because positivistic notions of EBP do not value qualitative research, which is one of the primary means by which service users are involved in research processes beyond a role as subject, there was seen to be a mismatch between EBP and participatory approaches to research. It was perhaps unsurprising, therefore, that many within the field were highly critical of the hierarchy of evidence’s failure to incorporate evidence gained from qualitative research.

Figure 2.2: Hierarchy of evidence-for-practice in qualitative research

Knowledge and information versus evidence

Glasby and Beresford (2006) advocated a model of “knowledge-based practice” (p. 281) and urged a rethinking of what constituted valid knowledge. Their proposed knowledge-
based practice model acknowledged the value of quantitative gold standard methodologies but also incorporated practitioner expertise and service users’ and carers’ experiences. Importantly, they proposed key strategies for addressing concerns expressed by critics in relation to the current model of EBP, namely its inability to reflect properly the context for individuals and to draw on the full breadth of expertise, experience, and evidence applicable to each service user. That they emphasised the role of service users in this process was of particular importance to the present study. However, it was difficult to see how the terminology of knowledge-based practice resolved the issues of evidence-based practice. If, as they claimed, what constituted evidence was contested, then what constituted knowledge was equally contestable.

Pawson et al. (2003) went some way to addressing this issue within the social care sector by classifying knowledge according to its source. Hence one might draw *inter alia* on organisational, practitioner, service user, and policy community knowledge as well as research or best available evidence. They highlighted that these types of knowledge were by no means hierarchical; different knowledge was needed for different purposes. Further, they suggested that, regardless of its source, the quality of social care knowledge could be tested by considering its transparency, accuracy, purposivity, utility, propriety, accessibility and specificity. Such classification exercises are attempts to respond to the failure of the social sciences to adequately consider the nature of the knowledge with which it works and to grasp the distinction between diverse modes of useful knowledge and types of evidence relevant to EBP.

From the evidence-based medicine perspective, Buetow and Kenealy (2000) suggested that EBP, specifically the hierarchy of evidence, failed to reflect fully the complex and multitudinous dimensions of evidence. They suggested that the focus on scientific evidence attempted to establish law-like relationships between phenomena
that contradicted the philosophy of science. They proposed a much broader definition of evidence-based medicine that took into account scientific evidence, theoretical evidence, practical evidence, expert evidence, judicial evidence, and ethics-based evidence. This critique highlighted the tendency to oversimplify the notion of evidence and, in doing so, to miss important contributions, such as the service-user perspective.

The debate on EBP brought into question the very purpose of research and knowledge. The classical perception of research was that its goal was knowledge production, not problem solving (Hammersley, 2003; Young, Ashby, Boaz, & Grayson, 2002). Potentially, processes such as systematic reviews misinterpreted the purpose of research to be associated with finding what works. Hammersley (2001) saw knowledge production for the purpose of policy making or problem solving as very different to that of pure or basic research. While EBP was proposed as a means for enhancing the relationship between research and practice, it was paradoxically, seen as a potential contaminant for its propensity to skew research towards particular outcomes pertinent to particular problems, rather than for unbiased knowledge production.

Solesbury (2001) offered similar cautions about the increasing tendency for research to be focused on ‘what works’ and for a growing demand, particularly in the United Kingdom, for research to be useable as well as useful. He highlighted the relationships between knowledge and power, especially in regard to policy making and public affairs, and the propensity for EBP to play into this tension, claiming that the move towards EBP was demand driven by consumers and that the social sciences should be cautious in their claims about its potential. His notion that EBP was a response to consumer demand was an important one to be tested in this study.

Newman (2009) saw the ‘what works’ approach as a reflection of changes to conventional power hierarchies in which institutionalisation had been weakened in the
face of strengthening market forces and a move towards greater user control. In this sense, it was seen as a demand-driven approach, but also one with the potential to stifle and standardise simplistic notions of what works. She described a dilemma for human service professionals in attempting to reconcile the emergence of a managerial ethos with the need to advocate for and empower service users. The way forward, she claimed, was “new forms of knowledge and expertise” (Newman, 2009, p. 73) that would challenge traditional notions of the professional as expert and the bureaucracy as all-powerful. Such new forms of knowledge, she suggested, needed to examine the value of service-users’ voices and choices. Newman (2009), Hammersley (2001) and Solesbury’s (2001) appraisals of the inadequacy of existing notions of knowledge and conceptualisations of EBP indicated the failure of EBP to serve the changing nature and demands of society, hence the need for the type of remodelling that this study sought to achieve.

The perceived move towards a risk society had implications for the nature and production of knowledge, reportedly with increasing demand for researchers to be more accountable for the research they conducted or the knowledge they produced. For example, Maasen and Lieven (2006) explored the way the production of knowledge in science blurred the boundaries between science and politics and the way researchers were being required to produce socially useful or accountable scientific knowledge. They posited that the participation of stakeholders, such as users and consumers, was one means of meeting this social accountability agenda and promoting modern notions of citizenship. However, they were cynical about the actual impact and visibility of the input of stakeholders on knowledge production, implying that its role was more one of public relations than cognitive change. Landry et al. (2001) demonstrated that mere involvement of stakeholders was not a reliable determinant of knowledge utilisation and
that it could not be assumed that having stakeholders involved in the research process would necessarily lead to improved utilisation of the research. More important in the social sciences were the researchers’ efforts to adapt the knowledge to fit the users’ needs and to engage directly with service users.

A level of confusion and misinterpretation about the meaning of evidence and its relationship to concepts such as knowledge and information was central to the inability of social sciences to come to terms with EBP. Models such as Glasby and Beresford’s (2006) knowledge-based practice reflected a fear that EBP failed to value or appropriately consider professional and service-user knowledge and expertise in the decision-making process. However, in many respects, this was an unfounded fear, and demonstrated a misinterpretation of Sackett et al.’s (1996) early definition of EBP, which emphasised the integration of “individual clinical expertise with the best available external clinical evidence from systematic research” (p. 71). Straus and Sackett (1999) later explicitly clarified that clinical expertise included the ability to effectively identify and apply a patient’s values within a specific situation, and that factors such as the relevance of the external, systematically researched clinical evidence to a patient’s situation must be considered in a shared decision-making process. The intention of an evidence-based process was that the most rigorous, relevant and reliable empirical evidence available inform a complex decision-making process which prioritised both practitioner and patient modes of expertise and values. Such a model did not require service-user expertise or consumer opinion to be considered within the hierarchy of evidence, because they were treated as vital factors in the decision-making process, and valued alongside empirical, systematically acquired forms of evidence.

Gray et al. (2009) described a confusion between evidence-based and information based processes and practice in the field of social work. They were critical
of a tendency for EBP to be oversimplified into decision making based on available information as opposed to its intended form in which evidence was examined through systematic review to build the knowledge on which decisions were based. They suggested that information was a fragmented, timely and unspecific process, whereas knowledge was a structured, universal and enduring state.

The distinction between knowledge, information and evidence was important to the study. The lack of clarity within the literature indicated that research with service users and service providers would reflect inconsistent understandings of the meaning and purpose of EBP and that the research would need to continually reflect on the meaning given to EBP by individual research participants and relate back to the fundamental definitions.

**Evidence-based policy making**

While the literature discussed thus far touched on evidence-based policy making, a more explicit examination at this level is important to clarify the meaning attached to EBP in this study. While at the individual client-treatment level EBP related to notions like informed decision making about treatments, at the level of policy making it concerned the ways in which governments and other authorities made policy decisions and determined funding priorities. Both levels of EBP were relevant to the present study.

Former Australian Prime Minister, Kevin Rudd, was cited as observing that evidence-based policy making sat “at the heart of … a reformist government” (Banks, 2009, p. 3), thereby implying that evidence-based policy making was more responsible, accountable, and open to innovation through the drive for policy coming from “experts” outside government. Certainly, EBP was an important tool in Third Way politics in the
United Kingdom under Tony Blair’s New Labour government, but whether it was essential to reformism has yet to be proved.

Historically, research was used in policy making in a variety of ways depending on the purpose of the policy-research relationship. Influential from the late 1970s onwards was Weiss’ (1979) work on the use of research and its relationship to policy, which helped to shape the models of policy making. She was credited with devising seven models depicting the relationship between the policy process and knowledge development as follows:

1. **Knowledge-driven model** wherein research led the development of policy.
2. **Problem-solving model** wherein research aimed to help find solutions to policy problems.
3. **Interactive model** wherein research involved complex and dynamic relationships between researchers and policy makers, with policy makers drawing on a range of sources of information.
4. **Political model** wherein research was used politically to justify or support certain stances, but did not have a direct influence over the opinion of the policymaker.
5. **Tactical model** wherein research could be used to stall decisions and where researchers might be blamed for unpopular policy or be misused to legitimise policy.
6. **Enlightenment model** wherein research stood at a distance from policy aiming to provide a frame for the way policy problems were considered such that its influence was subtle and indirect.
7. **Enterprise model** wherein research was an intellectual enterprise that produced knowledge for society.
Young et al. (2002) advocated an enlightenment model, positing that evidence-based policy making was only one part of the knowledge utilisation and dissemination process. They believed that the broad goal of an informed society was important and that the enlightenment model most accurately described the purpose of research as being to inform debate rather than solve social problems, a premise supported by others (Black & Donald, 2001). Weiss (1979), however, was cautious about the virtues of the enlightenment model, suggesting that it might fail to infiltrate decision-making processes and might result in lower quality research gaining more attention.

Nutley, Walter, and Davies (2007) employed the seven models as a framework to consider the challenges and strengths of evidence-based policy making. They also defined evidence for policy making as being either supply or demand driven. The supply side focused on issues relating to the production and dissemination of research, while the demand side concerned accessibility and the willingness and ability of policy makers to use evidence. Characteristic of both was the politicisation of research and potential for research to be used or misused in knowledge production processes and public service provision. As such, they demonstrated the importance of valuing not only the direct or instrumental uses of research to inform practice and policy, but also more subtle ways that research could shape understanding and attitudes. They, like others in the evidence-based policy making field, explored the inherently political nature of policy making and challenges for the application of research findings. The propensity for research to be used to justify or stall a political decision represented a misuse of findings. They referred to a continuum of research utilisation that stretched from conceptual uses, such as awareness and understanding of knowledge, to more instrumental uses like practice and policy change. In so doing, they referred back to the central concern for evidence-based policy making literature, which the seven models
attempted to conceptualise; that is, the unclear purpose of research and how this fits with policy making and problem solving.

Evidence-based policy making was seen to have appeal because of its potential as an objective and neutral process that countered the political nature of policy making. However, the selection and determination of what counted as evidence and the way in which that evidence was used was considered far from value free and was based on a range of assumptions. This was exemplified by Marston & Watts in discussing the ways in which evidence-based juvenile justice policy had relied on particular theoretical frameworks and theories of child development and had tended to provide over simplistic technical solutions to complex issues of social responsibility and government mismanagement (Marston & Watts, 2003). There was a perceived risk that in failing to recognise and acknowledge the assumptions and values underlying evidence-based policy making, stereotyping and marginalisation of subordinated groups might be reinforced. Further, they considered that the notion of a hierarchy of evidence could lead to an undervaluing of knowledge such as that derived from lay citizens (Marston & Watts, 2003).

The development of the Campbell Collaboration for the social sciences was an attempt to resolve problems regarding the politicisation of evidence and the difficulty in deciphering relevant, quality information. Based on the Cochrane Collaboration, which published systematic reviews of the effects of medical and healthcare interventions, the Campbell Collaboration sought to produce and publish systematic reviews of “research on the effects of social and educational interventions … [and in doing so] … meet challenges posed by evidence-based policy” (Petrosino, Boruch, Soydan, Duggan, & Sanchez-Meca, 2001, p. 14). Since its inception in 2000, it was difficult to determine the impact of the Campbell Collaboration, but it was obvious that it was a long way
from ingratiating itself into standard practice as the Cochrane Collaboration had done in the medical field. It had a focus on ‘what works’, a popular catchcry not yet an agreed-upon basis for determining social and welfare interventions because of its limited ability to grasp the context and draw out the mechanisms that made an intervention or program successful (Newman, 2009; Pawson, 2006).

The Campbell Collaboration attempted to overcome challenges associated with the high quantity and potentially dubious quality of research evidence available and for analysing and considering this evidence within the limited timelines and resources available for policy making (Marston & Watts, 2003; Young, et al., 2002). Young et al. (2002) asserted that much of the high quantity of evidence was often not taken into consideration by policy makers, not only because of poor quality or irrelevance, but also because policy making was not a linear, rational process. There were a range of social, economic, and political pressures on policy makers that shaped how decisions were made and militated against the impact of research evidence (Black & Donald, 2001). Young et al. (2002) claimed that evidence had a more valuable role as a democratic tool rather than a decision-making one in that it could help to inform public debate on important social issues.

The value of evidence to the policy-making process was seen to be its potential for more accountable and less-biased decision making and allocation of resources, ultimately to achieve more efficient and responsible use of public resources. However, the literature indicated that the premise for evidence-based policy making had been oversimplified, because the inherently political nature of policy making was at odds with the supposedly objective processes of research and knowledge production. Moreover, where reliable and rigorous evidence acted as a stimulus for debate and
discussion, rather than as a decision-making tool, it was seen to have potential to enhance democracy.

**Service-user participation and EBP**

Fundamental concerns identified within the literature included the potential for EBP to devalue knowledge gleaned from service users or lay people and scepticism about the ability for an evidence-based model to be transferred from the medical to the social sciences where perceived issues of complexity and context had to be taken into account. There was a small but growing body of literature that considered the role of the service user, client or layperson in the process and the ways in which their involvement related to fundamental concerns with EBP. While the notion of participation contained in the literature was not conceptualised in the type of broad, structural model entailed in parity of participation, this literature was crucial to the present study because it contained the beginning ideas of participatory models of EBP. This study considered EBP and its relationship with the service user at an individual treatment level - or that between client and practitioner - and also at the level of policy making and representative involvement by service users.

While the literature on service-user participation in EBP-specific processes was limited, there was a growing body of work relating to service-user participation more generally in research and decision-making processes. This work described the aims of service-user participation pertaining to securing the rights of citizenship, empowering consumers, redressing power imbalances between clients and professionals, and seeking knowledge for the purposes of action and change (Baxter, Thorne, & Mitchell, 2001; Boxall, Warren, & Chau, 2007; Braye & Preston-Shoot, 1995; Faulkner & Thomas, 2002; Turner & Beresford, 2005). The type of process and philosophy described by
Gambrill (2006b) and Shlonsky and Gibbs (2006) placed the client at the centre of the process, operating on the premise that EBP could enhance the client’s decision-making capacities. EBP, in this sense, could be a significant tool for advancing the goal of better-informed and better-serviced clients through its capacity to enhance client choice. In this sense, service-user participation in EBP related to individual decision-making processes.

One literature review and consultation study on choice and decision making for mental health service users found that those who were adequately informed and actively involved in decision-making processes were more satisfied with services than those who were less informed and uninvolved (Warner, Mariathasan, Lawton-Smith, & Samele, 2006). Warner et al. (2006) noted that this type of active service-user involvement required an additional investment of resources. This same review, however, indicated that there was inadequate evidence to determine whether service-user participation led to changes in services (Warner, et al., 2006). Despite lacking any proof of improvement to services, the intrinsic value of the participation was seen in terms of the “empowerment” of participants, a goal which was often referred to by advocates of service-user participation (Baxter, Thorne & Mitchell, 2001, p. 52; Beresford & Branfield, 2006, p. 440; Beresford & Evans, 1999, p. 673; Honey, 1999, p. 262).

Hope (2002) described “evidence-based patient choice” in psychiatry as important in enhancing the client’s power and in achieving “good” outcomes according to the client’s values (p. 100). One of the unresolved challenges for EBP was to identify the concrete outcomes that a treatment or policy should be attaining. Success was variable depending on which stakeholder determined the outcomes and whether there might be significantly different priorities for funding bodies, service providers, and service users. However, by Hope’s (2002) analysis, the role of the service user was to
work with the professional to identify and prioritise outcomes. A good outcome reflected the values of the patient or client and gave the client evidence from which to make informed decisions or choices about treatment.

This call for outcomes to be goals determined in consultation with the client or service user was echoed in the field of disability research. Sapey (2004) suggested that “if these [outcomes] are not first agreed with disabled people, there is little point in seeking evidence for effectiveness” (p. 157). What works was considered irrelevant if it failed to achieve the goals and reflect the values of the client. He highlighted that the politicisation of disability could not be separated from any evidence-based approach to research and practice, and that a model of EBP must correspond with the principles of the social model of disability in order to have resonance and relevance. Sapey’s (2004) discussion highlighted that EBP will struggle to gain a foothold in human services if it is not conceived of in terms that support service-user participation practices and support philosophies which have gained prominence through advocacy and lobbying by service users in sectors such as disability.

The notion of client choice and the potential empowerment of service users through greater involvement in and better informed choice, featured most prominently in mental health and disability related literature (Bolzan & Gale, 2002; Campbell, 2001; Faulkner & Thomas, 2002; McAllister & Walsh, 2004; Wareing & Newell, 2002). It was in this area that the process of EBP as a client-centred, bottom-up approach was seen to be important. Decision making entailed more than making a choice from a rigid menu of interventions deemed appropriate or ‘shopping around’ for services. It related to choice in, and control over, the way that interventions were resourced, managed, delivered, developed, and researched.
In contrast to the individual client’s relationship with EBP, representative models of participation in EBP have received limited attention to date. The examples available described varying degrees of participation in EBP, from service users in an advisory capacity, to service users as researchers leading the systematic review process. There was also a body of related work describing the value of service-user involvement in research processes (Baxter, et al., 2001; Beresford, 2007; Beresford & Evans, 1999; Davis, 1992; Entwistle, Renfrewe, Yearley, Forrester, & Lamont, 1998; Faulkner & Thomas, 2002; Griffiths, et al., 2004; McLaughlin, 2005; Nelson, Ochocka, Griffin, & Lord, 1998; Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006; Turner & Beresford, 2005).

Baxter et al. (2001) undertook a comprehensive study of “lay involvement” (p. 2) in research across a number of sectors, mainly in the United Kingdom. They suggested that lay involvement in research was “an important way for people to influence practice within health and social care” (p. 1). Like Arinstein (1969), they proposed a range of levels of participation ranging from passive to full ownership and suggested that the quality of the participation was closely related to the empowerment of the participants, their level of control, and the accessibility of the language and structure of the research. Their manual detailed effective strategies for getting laypeople involved, providing an indication of how service users might be involved in the generation of evidence, and the value of the layperson’s “voice” (p. 17) as a source of evidence. However, they failed to analyse fully the power relationships and decision-making processes implicit in EBP and the impact of layperson involvement at a structural level.

In the United Kingdom, the Social Care Institute for Excellence (SCIE) considered and developed guidelines for the participation of service users in EBP
processes, such as systematic reviewing (Coren & Fisher, 2006). They saw the involvement of service users in such processes as important for ensuring the relevance of the review process, achieving accountability, empowering service users, steering the project, and identifying sources of literature not found through conventional review methods. Another publication from SCIE provided examples of the diversity of ways in which service users could potentially be involved in the systematic review process. In one systematic review of consumer perspectives on electro-convulsive therapy, a range of service-user groups participated on a reference group to guide the review and also to collect user testimonies and other forms of user-based evidence to contribute to the review (Carr & Fleischmann, 2007). This methodology combined a conventional systematic review process for collecting and analysing relevant, quality literature with systems for incorporating user perspectives, thereby attempting to balance clinical and academic research with service-users’ needs. Other reviews included service users on advisory groups to make decisions about the criteria and content for reviews. Researchers used the knowledge held by service users to interpret and implement the findings from a review (Rees & Olivers, 2007; Stewart & Oliver, 2007).

Braye and Preston-Shoot (2005) claimed that a strict application of the hierarchy of evidence provided little room for “the involvement of service users, other than as research subjects” (p. 179). They considered service-user input important for enhancing research and assisting in the application and dissemination of research findings. However, they observed that as the systematic review process moved beyond positivistic notions of evidence and started to deal more effectively and inclusively with qualitative research, there was real potential for researchers to adapt their methodologies to include service-user involvement. This was considered part of the evolution or ongoing work of improving the systematic review process.
In the United States, Mullen et al. (2007), in investigating why clinicians failed to use research in social work practice, suggested that it might relate partly to the limited success of top-down implementation strategies. To increase the uptake of evidence in social work services in the United States they suggested that a combination of top-down and bottom-up approaches be used. As an example, they outlined the Texas Benefit Design Initiative where stakeholders, including service-user representatives, were brought together to reach consensus on those areas where there were gaps or inconsistencies in the available evidence (Mullen, et al., 2007, p. 6). This example demonstrated growing recognition of the potential role of service users in improving the relevance and usability of evidence for practice. However, there was limited evidence on the impact of service-user participation on EBP implementation practices or on outcomes for clients (Mullen, et al., 2007).

The positing of randomised controlled trials as the principal form of evidence was seen to be a problematic notion for EBP in the social sciences, particularly in regard to the ethical considerations for research participants. In evidence-based medicine Hanley, Truesdale, King, Elbourne, and Chalmers (2001) studied the impact of consumer involvement in randomised controlled trials, not as subjects of research, but as active participants. They surveyed a range of clinical research trial centres in the United Kingdom and discovered that there was a growing tendency to involve consumers. The most identifiable benefit from consumer involvement was to produce relevant research that matched the consumer agenda. This finding was confirmed in other studies of consumer involvement in healthcare research, where there was some indication that involving consumers in research might lead to policy, research, and practice that better met clients’ expectations and improved accountability and transparency. However, there was no evidence in this body of literature that involving
consumers in research had any real impact on decision making or that it affected the healthcare and welfare agenda more generally (Faulkner & Thomas, 2002; Nilsen, et al., 2006; Oliver, et al., 2004). Weinstein’s (2010) work, co-produced with mental health service-user researchers, reiterated the claim that service-user involvement in research improved relevance and afforded "insights into what it feels like to experience mental health problems" (Leiba, 2010, p. 160). Such claims had been previously made by service users with experience of research, but with little empirical backing.

The status of expert was fluid and not held by one group. Rather expert knowledge was “open to reappropriation by anyone with the necessary time and resources to become trained” (Giddens, 1994, p. 91). In the United States, consumer groups, such as the National Alliance on Mental Illness (NAMI), assumed expert roles in relation to EBP. NAMI had become an advocate for EBP in mental health service delivery, providing resources for consumers and carers to assist in identifying, accessing, and advocating for EBP (National Alliance on Mental Illness, 2007). As such, it was apparent that service users could play a significant role in generating demand, and it might be that practitioners and policy makers would become increasingly obliged to engage in EBP to satisfy consumer expectations. Solesbury (2001) asserted that “patients, parents, students, clients, customers of all kinds are less and less inclined to take professional views on trust” (p. 6). He suggested that, in order to gain the informed consent of patients, practitioners should provide detail in regard to what the intervention entailed, why it was appropriate and, the intervention’s likely efficacy. The professional was no longer seen as an unquestionable expert and service users were expecting greater levels of information and evidence.

In the field of science, Stilgoe et al. (2006) saw the gaining of trust as an essential motivation for opening up expert advisory panels to lay membership. They
also described ways in which the internet led to a globalisation of prior local knowledge and the way in which the public was becoming more informed about issues affecting them. Shaw (2002) cited De Swaan’s exploration of the notion of “proto-professionalization” (p. 289) whereby laypeople adopt the language and concepts of medical professional as a filter through which they analysed and considered their own issues and illnesses. This is pertinent in light of a supposed increase in accessibility to information, particularly via the internet. This work suggested that, before they had even had any contact with a practitioner, clients had obtained information about their condition and potential treatment options. Patient expertise was also an important consideration relating to the patient’s unique knowledge about their condition and about how it felt and manifested itself. Bolzan and Gale’s (2002) research similarly revealed the ways in which mental health service users and older people viewed themselves as experts on their own conditions, possessing unique knowledge that had the potential to benefit not only themselves, but also others in their peer group.

The limited literature on service-user participation in EBP and other related research practice, therefore, revealed potential roles for service users in the supply and demand sides. On the demand side, they were proving to have a significant role as consumers with growing interest in and access to information demanding that professionals should use and provide accurate evidence to support their treatment and service interventions at an individual level. Organised, representative groups might also increase the pressure for EBP, such as the activities of NAMI in the United States. On the supply side, potentially, service users could be involved actively in the generation, interpretation, and dissemination of evidence and could be a source of evidence.

However, the notion of service user was broad and the level of interest and capacity to engage with EBP in any type of role would vary significantly depending on
the type of service or intervention and individual circumstances. Assumptions about service-users’ access to technology, such as the internet, must also be considered in determining their current and future role. As discussed in the next chapter, rather than being a neutral process, service-user participation and its goals related closely to empowerment and rights movements that might have quite different agendas to EBP.

EBP implementation in Australia

Within literature and policy documents pertaining to Australian human services, the term ‘evidence-based’ had gained popularity, although it was not clear that the term was used in the way conceptualised by those academics and critics writing about EBP internationally. The former Australian Prime Minister expressed a commitment to evidence-based policy making (Banks, 2009). Within federal departments, such as the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), one of the key concepts emerging in government reports and papers was the importance of “building the evidence-base” (Macklin, 2008, p. 38). This was reflected not only in rhetoric, but also in various funding grants to support research, in areas such as Indigenous health and wellbeing, children’s services, and homelessness intervention and prevention (Department of Families Housing Community Services and Indigenous Affairs, 2009b; Macklin, 2008; Plibersek, 2009).

There was limited literature describing the implementation of EBP in Australia, particularly in the social and human services sector. Gray et al. (2009) suggested that within social work EBP was more likely to be implemented where the practice was aligned with health and mental health services. Their analysis indicated that EBP had limited impact on actual practice within social work in Australia and that Australia’s research infrastructure was poorly equipped to support the implementation of a rigorous
model. They suggested that the pressure upon service providers, especially those receiving government grants, to produce evidence of service effectiveness resulted in the poor quality of evidence. Evidence was produced to justify ongoing funding, rather than as a tool to guide and improve practice or contribute to new knowledge.

Gray and McDonald (2006) claimed that increasing interest in EBP within social work was part of an ongoing movement to legitimise the profession by increasing its scientific foundation and addressing perceptions of irrationality. They also examined its place within the neoliberal influence on social and welfare services, observing that EBP was a response to the new public management regime’s call for improved accountability and performance. It should be noted that they saw EBP as a poor tool for improving practice and that ethical reasoning was considered a more relevant means of achieving accountable and high quality social work practice, which better accounted for the complexities of the human or community services environment.

Murphy and McDonald’s (2004) research on rural practice confirmed that EBP was more likely to be implemented where there was an alliance with health and mental health. They described the pressure on social work practitioners in Australia to adopt EBP practices as a means of legitimising social work, particularly within multidisciplinary teams. In this setting, the institutionalisation of EBP within the health sector exacerbated tensions between health and social service practitioners. Their research indicated a limited understanding of EBP by rural social workers and perceived conflict between practices of EBP and contemporary social work practice approaches. This assumption was scrutinised in the case studies in the present study, where mental health service-user and professional understandings are compared and contrasted with those of service users and professionals in the homelessness sector. In the United Kingdom it was generally acknowledged that EBP had had a significant impact on the
clinical aspects of mental health, due to its proximity to the medical sciences (Geddes, 2000).

Within various human service sectors in Australia, the language of EBP seemed to be gaining popularity, although the literature told little about its impact on practice. This is explored in greater detail in the case study chapters. Within the homelessness sector, the language of EBP emerged in the national conference on *Housing When? Evidence based practice for solving homelessness* (National Homelessness Information Clearinghouse, 2009). Within the mental health sector, for example, organisations like the *Mental Health Association* (Mental Health Association NSW, 2008) referred to the reports that informed their policy decisions as their evidence base.

**Conceptualising EBP in a social justice framework**

The most compelling argument for a model of EBP was that it could provide transparency and accountability to clients by offering informed choice. This client-centred model related to the individual level of treatment, and aimed to provide the client with an opportunity to make a choice based on best available evidence. This required transparency about gaps and inconsistencies in the evidence. Also, due to problems with attaining the standard of evidence deemed most reliable and rigorous as per the hierarchy of evidence, social scientists have tended to utilise a range of qualitative and quantitative studies. This was referred to in some of the literature as an evidence-informed model in order to distinguish it from more rigid models of EBP (Chalmers, 2005).

In this literature review, EBP processes were also considered at a level above that of individual client treatment. A practitioner might not even have the option of offering an intervention or service to a client if it were not supported and resourced by
authorities, such as government service providers, funding bodies or even senior managers within service organisations. The options available to a client in a specific situation were filtered through levels of decision making and EBP. The importance and influence of processes relating to use of best available evidence at the level of policy making were shown.

The traditional or empiricist model of EBP was seen to be aligned more closely to the model of evidence-based medicine and forms in which the hierarchy of evidence was strictly applied. Under this model, it was considered irresponsible for a practitioner to offer a service or treatment that did not meet rigorous standards of scientific testing. This type of debate has played out in the Australian medical industry, in which questions were raised as to whether public funds should be made available to practices that were not scientifically tested (Van Der Weyden, 2010). It was this type of model that seemed to meet the most resistance in the social sciences. There was concern that a range of otherwise quality forms of evidence and decision-making tools would become secondary to evidence acquired through scientific testing models. However, it was difficult to determine whether this type of EBP model was being considered or implemented at either the level of policy making or individual client treatment within Australia.

The present study considered EBP within the more flexible, pragmatic definition, in accordance with the practice and policy models emerging in Australia. The terminology of EBP per se was not important to this project. Any processes that drew on research evidence in some type of recognisable or systematic way in order to make decisions regarding the design or delivery of social services and social policy were relevant to this study. It was open to the prospect that EBP in its current forms, flexible or otherwise, should be replaced by an alternative model. Evidence-based policy
making was also included in the modelling and the term ‘evidence-based practice and policy making’ was used in some literature that discussed these processes at the client and representative service-user levels (Gambrill, 2006a).

A contribution to social justice was appropriate to consider as a broad objective for tools such as EBP, because individual client outcomes had been shown to be almost impossible to conceptualise. This made it difficult to determine whether or not an intervention had been successful or effective. Often the service provider and client had differing opinions on the goal of treatment. The increased application of performance measures in welfare and social services in Australia demonstrated this conflict. For example, the efficiency of government-funded accommodation services had been evaluated in terms of throughput or “the number of people accommodated in one place over a specified period” (Johnson, Gronda, & Coutts, 2008, p. 150). Such a measure did not consider whether clients exited to substandard or long-term accommodation. While the outcome per service provider or, indeed, per funding body, might relate to one measurable aspect, such as attainment of a housing placement, it was not clear that this accurately captured whether the intervention had been successful, effective, or efficient. Was the accommodation suitable in terms of size, quality, location, and security? Had issues regarding health, family, and income been addressed? What was the likelihood that homelessness would reoccur? Considering the economic, cultural, and political domains within a social justice framework considers the success of an intervention in terms of whether or not it had enabled an individual or a group of people to achieve greater access to the opportunities available in a society.

If EBP were to live up to its aspirations of achieving transparency and accountability for service users, then it would need to demonstrate clearly where and how the service user factored into this process. It was a process undertaken with the
client rather than something *done to* a client, or a product delivered. While definitions like that offered by Sackett et al. (1996; 2000) claimed the importance of a bottom-up approach that valued patient choice, little attention had “yet been given to the questions of how to combine evidence with clinical experience or consumer perspectives” (Trinder, 2000a, p. 214). The relationships between researchers, policy makers, practitioners, and service users needed to be considered from evidence-based policy making through to individual treatment-based EBP. Decision making was a complex process that was not entirely rational and the most rigorous evidence in the world might not be enough to convince a client to undertake a treatment, especially where they were not confident and satisfied with the way in which they had been engaged in the treatment process.

The limited capacity for EBP to flow from contextualised evidence - and to deal with the gaps, inconsistencies, and sometimes flawed nature of evidence - was widely criticised. It was posited as a reason for the slow uptake by social services in general and inspired calls to reconsider the hierarchy of evidence in particular (Glasby & Beresford, 2006; Mullen, et al., 2007; Pawson, 2006). There was seen to be an uneasy relationship between the positivistic model of EBP and the pragmatic model favoured in the social sciences where the issues to be resolved were complex, unique, and highly individualised. There was a risk in pushing a model that seemed, at least anecdotally, to be gaining ground, especially one that did not consider effectively the nature of the social sciences and its rejection of the systematic use of evidence. It was highly likely to result in lost opportunities to improve practice and policy. By conceptualising EBP within a social justice framework, the process could be reconnected with the values and aspirations of social service delivery and policy making. The literature hinted at the potential for EBP to contribute to social justice aims related to human service delivery,
particularly in relation to service-user empowerment and involvement. The literature failed, however, to conceptualise adequately the importance of the role of the service user in EBP and to relate this to a broader social justice framework. The present study attempts to redress this gap.
CHAPTER 3

Service-user Participation Literature Review

This literature review clarifies the historical context of the concept of service-user participation given that the terms ‘service user’ and ‘participation’ have broad, diverse, and contested meanings. In this review the development of service-user participation was tracked to the contemporary situation in Australia, where one of the fundamental failings of efforts at service-user participation was the poorly and thinly constructed conceptualisation of the term. A second failing was lack of empirical support for claims made regarding service-user participation. This review examined the ways in which the goals of service-user participation could be realised effectively through understanding and adopting a more complex, structural notion of participation. It considered the emerging value of service-user participation and traced its history to citizenship and democratic theory. It showed how the existing model of service-user participation developed from these roots, and where the strengths and failings of current models of service-user participation lay. A rights-based approach to service-user participation failed to address real structural inequality, and instead doled out minimal power to service users, with authorities and professionals retaining control of policy making and practice. Similarly, the notion of participation as a consumerist activity, which gained prominence under neoliberal ideals, failed to consider the needs of the most vulnerable and lost much of the strength of citizenship movements. The notion of parity of participation was introduced to the review to strengthen the notion of service-user participation and to conceptualise this type of activity within a social justice framework.
This more richly conceptualised notion of service-user participation was then examined in relation to EBP to establish the theoretical framework for developing the hypothesis of the study.

This literature review sought to highlight works which shaped contemporary debates and thought on participation in Australia. Because, in Australia, service-user participation strategies and mechanisms often derive from the health sector, these materials were also considered where relevant. A more detailed description of the literature review methodology is included in Chapter 4.

The activities or processes that constituted service-user participation were difficult to define. First, it was difficult to group together the broad and diverse categories of people known by a range of terms, including ‘service users’, ‘consumers’, ‘customers’, ‘clients’, and ‘survivors’. Generally though, the terms were considered to describe people who currently did, or who were eligible to, access a service and usually included carers. Secondly, ‘participation’ was seen to be a similarly broad term, commonly referred to as involvement, activity, consultation or partnership within which there were varying degrees and levels of user control.

**Participation as a right: Citizenship and democracy**

Hegel (1942) explored the ethical nature of society, describing a system of interdependence by which “the livelihood, happiness, and legal status of one man is interwoven with the livelihood, happiness, and rights of all” (p. 123). For Hegel, the state was the ultimate realisation of the idea of ethics. From this Hegelian perspective it was apparent that, without the opportunity to participate in the state, self-realisation was not possible. Non-participation was considered as something close to dehumanising. As such, the active participation of members in a democratic society was seen to be crucial
from an ethical perspective and fundamental to the very nature of democracy. The Hegelian interdependence perspective and the aspiration to increase the level of participation of others was an important one and certainly was not selfless. The motivation to improve the conditions for those not enjoying the same access to livelihood, happiness, and rights was driven by an individual’s desire to improve his or her own dependent wellbeing.

This notion of participation as a democratic right was integral to the development of models of service-user participation in research and other activities associated with the generation and dissemination of evidence. The right to participate, especially in the formulation of policies and programs that affect a person directly, was seen as essential to a democratic society (Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998). Thus, a political mandate motivated the inclusion of service users in the generation and implementation of evidence. Beresford and Branfield (2006) claimed that the service-user movement, particularly in the United Kingdom, emerged as a response to the right-wing politics that dominated the 1970s and 1980s and that these social movements were based on a “philosophy of democratization and empowerment” (p. 438). Their understanding of this notion of participation as a right versus participation as a consumerist activity is explored below.

Charles Taylor (1989) described a notion of dependence similar to Hegel’s (1942) interdependence model, or what he referred to as “webs of interlocution” (p. 39). He noted the tendency, in recent times, within the United States, to move towards individualisation and self-reliance, but drew out the contradictions in this notion and the inevitability of even individuality becoming part of a web. Taylor’s (1989) work was also interesting for its analysis of the constitutive good and its attempt at understanding the moral and ethical construction and value of the notion of good. Importantly, he
suggested that while there was a level of agreement within society about moral good, such as the general agreement that murder was morally wrong, there was an underlying tension and lack of resolution about constitutive goods. This was important to the analysis of concepts such as participation and empowerment in which the value or rightness of the approach was often assumed without properly considering its purpose and construction.

T. H. Marshall (1963, 1992) tracked the development of three key elements of citizenship, emerging in chronological order, civil rights, political rights, and social rights. Marshall (1992) claimed that citizenship was a status bestowed on those who were full members of a community. For him, all who possessed this status were equal with respect to the rights and duties with which the status was endowed. As such, citizenship represented obligations and privileges that constituted membership in a society. Of interest was his analysis of the concurrent rise of capitalism and citizenship, in which he claimed that it became possible for governments to relinquish obligations in terms of social protection on the basis that individuals had increasing capacity to “engage as an independent unit in the economic struggle” (p. 90) This was an important precursor to the notion of the client as “consumer”, discussed below. He suggested that social services were important for their role in equalising status, more so than equalising income, and that social services were a means to provide access to quality of life. His framework of citizenship was similar in many respects to Fraser’s (2000, 2008a) model of parity of participation explored later in this chapter.

The notion of empowering and ensuring active participation of those who used social services had its roots in citizen rights and emancipatory movements. According to Alway (1995), Marx envisaged the “proletariat” as the key to transformation of the capitalist society and saw the organisation of workers into politically active
revolutionaries as the inevitable route to socialism. Workers were considered “both commodities and the producers of commodities” (Alway, 1995, p. 18). The notion of economic participation was crucial to this understanding and, like Marshall, Marx highlighted the complex relationships between citizenship and capitalism. For him, economic participation was a potential source of power for citizens, as essential components of the production process, and a means of repression whereby the wealthy retained and built power.

Arnstein (1969) was one of the early writers to consider the manipulative propensity of participation practices. Arnstein’s (1969) “ladder of citizen participation” (p. 216) was one of the most influential descriptions of different levels of participation. It showed a progression from forms of non-participation, such as manipulation, to tokenistic participation practices, such as consultation, up to citizen control as the highest degree of citizen power. Hers was a model in which effective participation was seen to reflect full citizenship and the realisation of democracy. The highest degree of participation was that in which citizens had control and the greatest freedom and capacity to exercise their rights, while the lowest forms were those in which, as per Cruikshank’s (1999) understanding, participation was used as a means to manipulate, placate and, ultimately, suppress citizen rights.

Cruikshank (1999) examined the way in which democracy led to individualisation and was highly critical of the way in which the social sciences and social reformers had created active participants or citizens. Lobby groups, service-user movements, therapeutic social service programs, and other such associations were seen to “get the citizen to act as his or her own master” (Cruikshank, 1999, p. 102). Her analysis highlighted that participation was not intrinsically positive and just, and that poorly conceptualised notions of participation which related to compliance and identity,
more than real changes in power and structure, were potentially harmful to the social justice goals of citizens. For Cruikshank, the risk of participation was that it didn’t actually change the power relationship. Rather, there was potential that authorities delegated a tokenistic type of power at their whim, which was used as a means to placate citizens and coerce their cooperation. Her work also reflected scepticism about notions of self-esteem and empowerment, and noted that the focus on these qualities seemed to increase control of the individual, but was often superficial and a distraction from real structural injustices and inequalities.

Barnes (1999) explored the role of user groups and the relationship between the “user movement” (p. 75) and citizenship, claiming that there was a re-emergence of community and citizenship in the wake of a focus on consumer-driven rights. Her analysis of mental health and disability user movements in the United Kingdom indicated three key ways in which collective action could support the expression of citizenship, including:

1. seeking to achieve social rights associated with the status of citizenship
2. providing a forum from which excluded individuals can contribute to the practice of citizenship, and
3. enhancing the accountability of public services to their citizen users (Barnes, 1999, p. 82).

User representatives were seen to work collectively to address issues of identity, discrimination, and political challenges, but also socially to become active and have a voice in the communities and societies in which they lived. Additionally, user groups were seen to contribute to good governance by holding authorities accountable for the provision of services that addressed need and were delivered in effective, inclusive ways. Barnes’ (1999) work was a useful summary of the aspirations for effective models
of participation in which the goals relate to structural and status change that reflect democratic and citizenship principles, more so than the individualistic empowerment of service users.

Beresford’s prolific work on service-user participation focused on empowerment, viewing participation as a realisation of citizenship (Beresford, 2007; Beresford & Branfield, 2006; Beresford & Croft, 1993, 2004; Beresford & Evans, 1999). He highlighted the political nature of participation and the importance of the relationship with the state, noting that, “People’s involvement is both the end and the means” (Beresford & Croft, 1993, p. 6). Service-user participation was seen to have value, not only as a tool for achieving change, but also as a process with the ability to empower and fulfill people. He was critical of consumerist approaches to participation and saw this as quite different from the democratic forms of service-user participation that sought genuine enhancement of partnerships with service users and afforded them greater power and rights in relation to the development of services and policy.

Reflective of much of the literature on service-user participation, Beresford’s work built on a notion of rights and empowerment that didn’t really get beneath the meaning of the concept and critically analyse its relationship to addressing inequality. It certainly acknowledged the potential for participation to be misused and to be enacted poorly, but did not examine whether and how participation fitted more broadly into the aspirations of social and welfare service delivery. This was an example of participation being treated as a “constitutive good” (Taylor, 1989, p. 91) and in doing so failing to capture what the vague notion of empowerment meant. It took as a given that a rights-based approach to participation was a ‘good thing’.

Participation was also perceived as a means to redress the power imbalances between service-users and professionals (Braye & Preston-Shoot, 1995, 2005). For
Braye and Preston-Shoot (1995, 2005) service-user participation was important to achieve anti-discriminatory practice and to ensure that states did not take over the roles of individuals and their families. Essentially it was a mechanism to attain and retain power.

The notion of the service user as either a citizen or a consumer was seen to result in two distinctive approaches to participation, referred to by Hickey and Kipping (1998) as the “consumerist approach” (p. 84) which was premised on increasing choice in relation to service provision and the “democratisation approach” (p. 84) which sought to include users as citizens in decision-making processes.

**Participation as consumerism: Choice and shopping around**

The conceptual clash between consumerism and citizenship was a recurring one in the service-user participation literature, with the two principles considered as fundamentally different motivations and models for user participation (Barnes, 1999; Barnes, Harrison, Mort, & Shardlow, 1999; Carr, 2007). Consumerism related to the neoliberal idea of choice and marketisation of health and welfare services. Under this model, participation was seen as participation in the market, and choice was exercised through decision making about which services to access. Individuals were considered to be empowered by their ability to exercise economic power. This was a very different notion of participation to that based on democratic rights and citizenship described in the preceding section.

Beresford’s (Beresford & Branfield, 2006; Beresford & Croft, 1993) work examined the often conflicting principles of participation based on consumerism and participation based on democratisation, recognising that these had very different motivations for including citizens and led to different outcomes for service users.
Beresford and Croft (1993) suggested that the consumerist approach to participation was concerned with commodifying people’s needs and was based on the concepts of individual choice and competition. In contrast, a democratic notion of participation was founded on the concept of empowerment, with civil rights and equal opportunity as primary goals. It was an important clarification, because both concepts of participation were often used interchangeably by policy makers or those initiating participatory strategies, despite the clear contradiction between the notions. The individualistic emphasis of consumerist approaches seemed at odds with the aspirations of citizen-based approaches which sought to increase the rights and reduce the subordination of marginalised groups, who were often those very same people who benefited least or were most vulnerable under market-based systems.

The emergence of neoliberalism in the United Kingdom led to a strong emphasis on service-user choice. Choice, in the form of consumer rights and shopping around for social services, was considered a form of empowerment for service users. The move towards a marketisation of welfare services reflected broader changes in social service delivery, such as more personally tailored packages of care and an ever blurring distinction between public and private service delivery and funding of services. The perceived benefits of such a system were the potential for the service user to have an active role in shaping service delivery and to be able to make decisions about accessing services and resources that best met their needs. In the United Kingdom this type of reform had been evidenced in practices such as personalised budgets, whereby rather than funds being allocated to a service provider, the service user makes their own decisions about how to use their funding allocation, a practice also likely to be trialled in Australia in the disability sector (Australian Government Productivity Commission, 2011). However, this type of practice was shown to potentially increase inequality, with
those people better resourced, funded and informed able to access higher quality services at the expense of the most vulnerable (Newman, Glendinning, & Hughes, 2008).

This notion of choice was strongly criticised for its failure to properly consider the needs and circumstances of the most vulnerable (Barnes, et al., 1999; Barnes & Prior, 1995). The choice-based system of social services was an individualistic approach which required the service user to have the resources and capacity to make informed decisions about services and treatments. Barnes and Prior (1995) claimed that, “A simplistic notion of choice as selecting between options cannot stand up to systematic analysis of the processes through which people come to receive and make use of welfare services (p. 58). Barnes et al (1999; 1995) saw service-user participation and collective action, not necessarily as a part of consumerism, but as an important tool for countering the inadequacy and disempowering consequences of a market-based approach to public welfare. Service-user participation was potentially a response to consumerism that could protect service users from the individualistic and potentially poor quality outcomes created through a market approach to social service delivery. They also noted that consumer choice in welfare services was problematic where there was no, or poor, information on which to base decisions, revealing the potential for EBP to function as a tool supporting improved levels of informed choice.

In Australia, the emergence of the neoliberal agenda saw the term ‘consumer’ replace notions of citizen participation, and the concept of consumer participation had become strongly related to notions of choice and rights within a market place (Pinches, 1998). Tobin et al. (2002) noted that the term ‘consumer’ had its roots in commercial enterprises where consumer satisfaction led to increased demand and, therefore, profit. However, human services were publicly funded and delivered with finite resources and
increased demand was not desirable. The type of economic relationship between consumer, choice and power in a commercial market place was not easily transferrable to welfare and other human services.

In writing about the disability services sector in Australia, Wareing and Newell (2002) suggested that choice had been posited as a substitute for a rights-based approach to participation, to the detriment of service users, and in contravention of the principles of national human rights instruments. While the notion of choice was considered broadly to be intrinsic to a good life, particularly within a capitalist society, the making of choices was a complex and highly contextualised activity.

**Empowerment**

The concept of empowerment was one that proved problematic to the notion of service-user participation. In many respects it was shown to be a misinterpretation of the notion of enhanced citizenship and democracy, because the assumption that participation would achieve these conditions disregarded the risk of tokenism, coercion, and manipulation. Twenty one years ago, Rees (1991) suggested that the notion of ‘empowerment’ was often cited but rarely understood or defined. He claimed that when asked to explain the term, many service providers reverted to clichés. This would appear to be the continued case in more recent literature. Hence, the term failed to explain how complex and political power relationships were being addressed and how the translation of practice to policy was considered.

White (1996) expressed concern regarding the potential misuse of the notion of ‘participation’ and claimed that “[s]haring through participation does not necessarily mean sharing in power” (p. 6). She suggested that by including users and vulnerable groups through participatory practices, there was greater ability to exert control. She
was also mindful of the potential for participation practices to treat people as homogenous groups, noting the importance of practices that deliberately sought to include the most disadvantaged and account for the differences and individuality of users. It was not considered sufficient to simply include those who self-nominated, but it was proposed that action should be taken to include the most marginalised, subordinated, and vulnerable people.

Cruikshank (1999) described empowerment strategies as “technologies of citizenship”, suggesting that they were a means “to act upon others by getting them to act in their own interest” (p. 68). Like White (1996), she was critical of strategies that sought to empower those who were perceived to be apathetic and powerless, suggesting that empowerment strategies had actually been used by both sides of politics to create compliant, active citizens necessary to maintaining models of democracy. She suggested that the very act of participation was political and, where it did not effectively consider the subordination and structural concerns of status, it could be used to appease and quieten, rather than give a genuine voice.

More recently, authors like Pease (2002) and Tew (2006) built upon Cruikshank’s argument drawing out multiple understandings of empowerment that could have negative and positive impacts on overcoming the oppression of marginalised groups. Both Pease (2002) and Tew (2006) drew distinctions between individualistic and structural notions of empowerment. The individualistic approach to empowerment focused on building an individual’s capacities and had been favoured by neo-conservatives as part of managerial strategies to achieve efficiency and reduce dependency. It related to the neoliberal approach to welfare that aimed to have individuals “stand on their own two feet” (Tew, 2006, p. 34). In contrast, structural notions were about oppressed groups recognising the forces that impacted upon them.
and seeking to gain greater control of their lives as a group. It acknowledged that certain groups had privileged access to resources and had greater power. While Pease (2002) noted that the concept of empowerment was fundamental to the nature of social work and similar professions, he saw a dilemma for social workers and professionals in relinquishing their expertise to an extent, by empowering their clients and, in effect, making their professional role less necessary. Empowerment was often seen as something done to people by professionals, in which case it was apparent the real power continued to sit with the professionals and the idea of greater equality through empowering practice was illusory. However, despite the contradictions and confusion implicit in the concept of empowerment, Pease (2002) saw opportunities for the dominant discourse to be challenged through mechanisms such as opportunities for service users to contribute their stories directly to the knowledge base, so that knowledge was not the domain of professional experts and so that service users had the opportunity to be guided by affirming stories. Tew (2006) connected empowerment with emancipatory practice and highlighted the complexity of these notions, indicating that empowerment should not be seen as the final point or realisation of success, but as the “direction of travel” (p. 49). As such, empowerment and participatory practices were revealed as complex and contested tools in working towards social justice, not merely rights to be aspired to as end goals.

**Has participation achieved what it set out to do?**

One of the problems with the poorly conceptualised rights-based and consumerist approaches that focused on empowerment was that much of this literature failed to demonstrate whether service-user participation had actually had an impact on decision making and whether it had generated positive change for service users. In many
instances, the assumption of participation as a tool for enhancing empowerment overlooked the basic question of whether participatory practices had actually achieved what they set out to do.

Carr (2004, 2007), one of the early writers on the relationship between EBP and service-user participation, considered the impact of participation practices on social services in the United Kingdom. Though an advocate of service-user participation, she was cynical about many attempts at participation and noted that, while in the United Kingdom service-user participation had become a legislated requirement in social service sectors, the impact of this had not been monitored or evaluated effectively. There was an ethical imperative for participation that had not been backed up by empirical evidence indicating which practices were actually effective. She perceived participation as a citizen’s right that was inherently political and was cautious of the way in which participation practices could be appropriated to subdue passion and conflict. Increasingly, service-user participants were expected to couch their participation in managerial terms rather than as a lived and personal experience. There was often an expectation that service users would ‘play the game’ of the practitioners and policy makers, participating in meetings and similar forums and using technical language, rather than practitioners and policy makers changing the way in which they did business to better accommodate the needs of service users.

The value of participatory practices was questioned where the nature of the participation disallowed the personal and emotional expressions that were intrinsic to service-user input (Barnes, 2008; Hodge, 2005). Hodge (2005) observed participatory forums between mental health professionals and service users, noting the way in which disparities in power played out through the professionals’ control over the agenda and construction of boundaries as to what was acceptable and unacceptable for inclusion in
the forum. Barnes (2008) was similarly critical of the tendency for participatory forums, particularly in the mental health sector, to discourage and even disallow highly confrontational and personal accounts: “Emotion cannot be ruled out of order and public officials cannot claim that good manners dictate that strong feelings be left at the door” (p. 477). The development of service-user participation strategies, and their attempted mainstreaming in countries such as the United Kingdom, was premised on notions of citizenship, and of seeking a fuller, more complete perspective on social and welfare issues. The emotional and highly personal nature of this participation, however, was not something that had been well accounted for and, as such, true participation had not been achieved because the power balance had not shifted.

The expectations of service users and those in roles such as policy making and research were not always seen to align. The classification of users as a group distinct from these professional categories was indicative of an ‘us and them’ disparity between service users and those in power, which culminated in unresolved questions regarding the value and place of user knowledge amongst more conventional modes of evidence derived from research (Boxall, Warren, & Chau, 2007). However, Boxall et al (2007) advocated for the pursuance of service-user involvement in research and policy making and a re-examining of the roles of academics and researchers to resituate user involvement and to more genuinely challenge social policy.

In an international context, where participation of local people had been considered a fundamental principle of community development practice, these strategies were shown to have the potential to be used as tools for perpetuating power imbalances between organisations and vulnerable people, thus promoting efficiency rather than empowerment (Cleaver, 2001). Because the actual power relationships were not addressed and the very real subordination of those vulnerable populations was not fully
understood, so-called participation strategies could potentially reinforce inequality through the selection of unrepresentative or poorly equipped participants, place unfeasible expectations on them, and be unaccountable for achieving outcomes because the act of participation was seen as a good thing in and of itself.

The term “tokenism” featured prominently in critiques of service-user participation strategies, suggesting that service users would be appeased by having a seat at the table, or being given an opportunity to participate, without actually having any real opportunity to influence decisions and affect change (Arnstein, 1969, p. 217; Cornwall, 2008, p. 270; Lindow, 1999, p. 169).

Cornwall (2008) described participation as an “infinitely malleable concept” (p. 269) and highlighted the way in which the failure to define and understand participation adequately led to a multitude of different practices and strategies, many of which did not guarantee that people were able or willing to express their voice. She used frameworks such as Arnstein’s (1969) ladder of participation to examine the multitude of practices that were referred to as participation, varying from those that merely provided information to those that purported to hand over control. Further, she explored the important question of “who participates” (p. 275), noting the issues with representativeness of participation practices. In reality, it was often impossible for every affected person to participate in decision-making processes, but the type of democratic representation aspired to by many participatory practices could fail due to existing power relations and lack of understanding of the workings, relationships and needs of the target populations.

Participation could be seen to have evolved from notions of citizenship as a means to ensure that citizens had a greater degree of power over the decisions and activities that affected them. However the stark warning from the literature was that
despite underlying intentions of empowerment and equality, participation practices had failed to demonstrate their effectiveness and had at worst indicated potential to be used as tools for undemocratic processes of control and coercion. The conclusion from this analysis of the literature was that while participation was important, there was much to be done to clarify the concept and develop policies and models that allowed for users to have a real role in creating change.

**Service-user participation in Australia**

Since the mid-1990s, Australian social services have experienced a ‘mainstreaming’ process of service-user participation, in which the language of participation has become commonplace in government and non-government sectors. The concept of service-user participation featured in most federal and state level policy and program documents, but in accordance with the literature analysed thus far, there was little evidence of the way in which this participation was evaluated and whether it actually impacted upon decision making within the Australian human and social services.

The Australian government tended to use the term “consumer” to describe users and target audiences of human services, often including carers within this definition, or using the term “consumers and carers” (Australian Government, 2009b, p. 84). Generally, the federal government established frameworks, strategies or standards in regard to policy areas that described the principles and standards for participation. These informed or guided participation policies at the state and territory or local government levels at which services were managed and delivered.

While this study examined the human and social services, the development of consumer-participation strategies in the primary healthcare sector provided useful insights and was certainly influential upon, and influenced by, developments in areas
such as mental health, disability, and aged care participation practices. The National Resource Centre for Consumer Participation in Health (2004) provided a useful collection of case studies, toolkits, and models regarding participation in the health sector. It also presented evidence highlighting that consumer participation was important, not only as an ethical practice, but also as one that was shown to result in better health outcomes for patients. Recently in Australia, particularly within the state of Victoria, there has been some acknowledgement of the failure to effectively evaluate the impact of service-user participation contributions to the implementation of health services, resulting in activities such as the controlled trial of service-user led training in the area of co-occurring mental health and substance use issues (Thomacos & Roussy, 2011).

Internationally, people with a disability and people with mental illness have been leaders in movements to increase the level of participation and the voice of consumers in human service development and delivery. This trend was reflected in Australian government policy in these two sectors.

The 2009 National Mental Health Strategy stated that people with mental health problems not only had a right to be involved in decisions about their own treatment, but also had “the right to contribute to the formulation of mental health legislation and policy, and to the design, implementation and evaluation of mental health services at national, state/territory and local levels to ensure that services comprehensively meet their needs, including from a cultural perspective” (Australian Health Ministers Conference, 2009, p. 12). The mental health policies, charters, and strategies for the various state and territory based health departments reflected and endorsed this principle. In a number of states across Australia, health departments had introduced teams of consumer consultants to work with patients, carers and service providers to
present feedback and information from the patient or carer’s perspective (Hunter New England Mental Health Service, 2010; Queensland Health, 2007). This practice illustrated the requirement for health and welfare information to be considered as more than scientific fact and to be contextualised within individual experience.

The NSW Department of Health funded the New South Wales Consumer Advisory Group – Mental Health Inc (NSW CAG) to act as a “bridge between consumers in NSW and our State and Federal Governments” (New South Wales Consumer Advisory Group - Mental Health Inc, 2008, welcome section, para. 2). It was a relatively formal mechanism for consumer input to policy making and practice, with the organisation undertaking statewide consultations and other activities to gain consumer input and acting as a source of information to consumers about mental health policy and strategy. The formal relationship between government and NSW CAG was indicative of the strong role that mental health consumers have forged for themselves as participants in practice and policy making.

Honey (1999) noted that the “growing emphasis on consumer participation in mental health services in Australia is also evidenced by the increasingly high profile of consumer advocacy groups, such as the Schizophrenia Fellowship, the Association for the Relatives and Friends of the Mentally Ill and Grow, as well as various illness-specific consumer support groups” (p. 258). Consumer-led advocacy and input to services appeared relatively well-established among users of mental health services. The Mental Health Consumer and Carer Forum comprised national consumer and carer membership and included representatives from a range of consumer and carer organisations and associations (Mental Health Council of Australia, 2009). It aimed to share knowledge and resources with members and stakeholders and to be a significant voice in mental health policy development.
The disability sector was at the cusp of significant reforms, with the drafting of a Productivity Commission report in February 2011 that recommended a national disability insurance scheme and proposed enhanced models of consumer choice and control, similar to the model of personalised budgeting implemented in United Kingdom (Australian Government Productivity Commission, 2011). This reflected the influence of neoliberal notions of participation as consumerism within that sector. The proposal for extended levels of consumer control and choice built on earlier national standards for disability services which highlighted the importance of providing opportunities for people with a disability to make decisions and take responsibility for decisions in regard to the services they received (Disability Service Standards Working Party, 1993). The NSW Government provided an example of the way in which these standards were adapted for local use by service providers, in the document *Standards in Action*. National standard three “Decision Making and Choice” was broken down into minimum standards, enhanced standards and practice guidelines which described the policies and practices required to ensure service-user participation in decision making at individual and service levels (New South Wales Ageing and Disability Department, 1998, pp. 301-314). Australia is also a signatory to the United Nations (UN) Convention on the Rights of Persons with Disabilities, which was the first UN Convention to involve people with a disability and non-government representatives in the creation of the Convention (Victorian Office for Disability, 2008). A range of consumer and carer groups for people with a disability operate in Australia to provide information, advocacy, support and policy advice, including People with Disability, Blind Citizens Australia, Disability Council, Vision Australia, and Carers Australia. As such the disability sector exemplifies the partnership between formal consumer groups and government agencies at federal and state levels.
Aboriginal and Torres Strait Islander services had one of the strongest policy focuses on participatory practice, as reflected in the 2009 *Closing the Gap* report produced by the Australian Government (2009a). It described the importance of working in partnership with Aboriginal and Torres Strait Islander communities and mechanisms such as the establishment of “a national Aboriginal and Torres Strait Islander representative body to give Indigenous Australians a voice in national affairs” (Australian Government, 2009a, p. 5). The principle of self-determination was an important one within policy and program development related to Aboriginal and Torres Strait Islander communities, and was indicative of a significant shift from the colonialist and paternalistic policies of the nineteenth and early to late twentieth century. It was interesting to note that in this service sector the language of consumer participation did not feature so prominently as ‘self-determination’ and ‘partnership’. This was a controversial area of policy. Activities such as the Northern Territory National Emergency Response, also known as ‘The Intervention’, in which the federal government assumed control over many remote Aboriginal communities in the Northern Territory and engaged the Australian Defence Force to support its activities, could be interpreted as a direct contradiction to the language of partnership contained in federal government policy. It was a case in which the potential for the language of participation to be mere rhetoric was highlighted.

The participation of young people was promoted heavily by governments at all levels, particularly through consultative mechanisms, such as youth forums and advisory groups. The Australian Youth Forum was the most recent incarnation (the former government’s version was the Youth Roundtable) which explicitly sought to avoid tokenistic consultation efforts of the past and to be action based, recognising that “young people are the best experts on young people’s lives” (Australian Government,
2008b, How does the AYF work? section, para. 3). There was an increasing emphasis on the use of social and online media to engage with young people and as a forum for consultation. However, despite the rhetoric, it was unclear how, and to what extent, the outcomes of such consultation impacted upon policy and the services available to young people. This was particularly so given that people under the age of eighteen lack the most tangible element of participation in the democratic process, namely the right to vote.

The NSW Standards for Substitute Care Services (New South Wales Department of Community Services, 1998) indicated that organisations delivering substitute care services should have policies and processes in place which ensure young people are appropriately informed and have opportunities to be involved in decision making. The independent, non-government CREATE foundation that advocates for and acts on behalf of young people in care included participation strategies involving young people with experience of being in care on the Board of Directors and coordinating youth advisory panels in each state (CREATE Foundation, 2008). This relationship exemplified the way in which participatory strategies in Australia relied on the partnership of government and non-government agencies.

From the time it came into power in 2007, the issue of homelessness was high on the federal Labor Party’s social and welfare policy agenda. The publication of The Road Home white paper was a significant step in outlining its policy on addressing the issue (Australian Government, 2008a). Contrary to the participation ethos of the above national policies, this document did not explicitly outline strategies for inclusion of people experiencing homelessness in program design or development, but looked to an advisory panel of academic and professional experts. At a state level, Housing NSW made more explicit reference to the participation of service users noting that it had
formal and informal mechanisms for promoting tenant input to policy and program development as a means of improving the quality of services and outcomes and ownership of service users over the program (Housing NSW, 2008). The NSW Premier’s Council on Homelessness specifically included two people who had experienced homelessness, to provide advice alongside academic and professional experts. The NSW Government also provided funding to the Public Interest Advocacy Centre to coordinate a series of consultations with service users to feed into its action planning process (New South Wales Government, 2009b).

The formalisation of homeless persons’ participation mechanisms was seen to be at the early stages in Australia. Community-based legal services had taken a lead in this process, based on principles of human rights and advocacy. In Victoria, the Public Interest Law Clearing House, through their Homeless Person’s Legal Clinic, had supported a homeless person’s Consumer Advisory Group since 2006 (Public Interest Law Clearing House, 2009). A similar model had been established in NSW in 2009 through the Public Interest Advocacy Centre’s Homeless Persons’ Legal Service, called Street Care (Street Care members, 2009). A local government body, The City of Sydney, provided pilot funding to this group. Unlike mental health consumer advisory groups, the processes for influencing and feeding into government policy tended to be less developed and formalised, and these groups were still in the developmental stages.

The 2009 aged care pension review undertaken by the federal Government exemplified the type of participation strategies employed by government (Department of Families, Housing, Community Services and Indigenous Affairs, 2009c). The advisory body to the review included representatives of peak bodies and consumer groups working alongside academic, government and professional sector representatives. Nationwide public consultations and focus groups also informed the
review. The rights and responsibilities of consumers of residential aged care services were set out in a national charter, which included the right to control over individual decisions as well as the right to have input into decisions about arrangements for residential care services (Department of Health and Ageing, 2007).

As EBP processes are developed in Australia, there may be potential for the type of participation strategies described above to build in a service-user perspective to research findings and to assist in strengthening research and evidence dissemination strategies that meet client needs and are more likely to be accepted by clients. There may also be potential for EBP to assist the advocacy and resource-building work being undertaken by consumer bodies, to develop more reliable information systems so as to enhance consumer access to information.

In Australia, non-government organisations have played a significant role in the delivery of human services on behalf of government as part of contractual or funding recipient type arrangements, through private or user-pays arrangements, or through non-government or charitably funded activities. Cox (2002) noted that, historically, there had been little distinction between public and private sectors in Australia, with government institutions generally working closely with voluntary and community agencies. While service-user participation was not mandated in the same legislative manner as the United Kingdom it had become an important part, in rhetoric at least, of the principle of human service delivery in Australia, reflected in both the government and non-government sectors whose work closely aligns.

**A social justice framework**

While the literature revealed an increasing frequency in the use of the terminology of service-user participation, it did little to clarify what change these participation
strategies sought or how they sought to achieve change. Therefore, the impact of participation was not demonstrated. As a component of citizen rights, the right to participate in policy making and programming activities regarding services that affect an individual, had come to be considered a type of constitutive good whose value had not been properly conceptualised or understood. Therefore it was prone to misuse and manipulation. As part of a move towards consumerism in the human and social services, the importance of service-user participation in addressing inequality and meeting the needs of the most vulnerable had been lost. As Australian human service policy makers and providers struggled to build the quality and effectiveness of services through tools such as EBP, it became apparent that there was a need to resolve the concept of service-user participation and to ensure clarity around the social justice ambitions of this type of policy and service delivery.

**Social justice and parity of participation**

Australian Indigenous leader Mick Dodson (1993) stated, during his time as the Aboriginal and Torres Strait Island Social Justice Commissioner of Australia, that:

> Social justice is what faces you in the morning. It is awakening in a house with adequate water supply, cooking facilities and sanitation. It is the ability to nourish your children and send them to school where their education not only equips them for employment but reinforces their knowledge and understanding of their cultural inheritance. It is the prospect of genuine employment and good health: a life of choices and opportunity, free from discrimination (p. 8).

Dodson gave a face to the somewhat ethereal notion of social justice and demonstrated what the result of effective social policy and programming might look like. Importantly,
he touched on the economic equality involved in social justice, while considering identity issues regarding the value of culture and political issues regarding discrimination and choice. His description captured the importance of social justice as a political, social and economic aspiration within Australian society. The ethical underpinnings of social justice are complex and contentious. Nancy Fraser (2005) posited that “parity of participation” (p. 73) was a means of conceptualising, understanding and working towards the complex goal of social justice. Parity of participation set a standard and defined social justice, which “requires social arrangements that permit all to participate as peers in social life” (Fraser, 2005, p. 73). It was set as an ideal, which recognised the ethereal and contested nature of social justice, to be seen not as a reduction or simplification of the concept, but as means for making social justice workable.

Fraser (2008a, 2008b) broke the concept into three constitutive domains: economic, cultural, and political and posited three crucial reparative mechanisms to achieve parity of participation; redistribution, recognition and representation. The framework responded to a tendency to emphasise the importance of identity struggles and prioritise the recognition of identity as fundamental to achieving social justice. This model did not underestimate the importance of recognition, but saw real dangers in group identity struggles that failed to recognise the heterogeneity of individuals and which reinforced stereotypes. Fraser (2001) proposed instead, a “status model” (p. 24) that focused, not on the group identity, but on the ways in which the status of people was subordinated. The cultural or social aspect was constructed, not according to a group identity, but in relation to the structural ways in which certain people were prevented from full participation in society. Furthermore, her framework suggested that redistributive measures were just as important as structural change to recognise status
subordination, recognising that social justice could not be achieved without ensuring that material and financial goods were allocated in a more equal way that sought to address imbalances and the inability of some to participate fully. Recognition and redistribution were the foci of Fraser’s earlier works, but her more recent consideration of the framework explicitly included representation, noting that measures to redress political subordination and incapacity of some groups to participate fully, or be represented, in the political process were crucial (Fraser, 2008b).

The separation of these domains has been contested. Swanson (2005) claimed that the separation of economic, cultural and political facets falsely implied that these operate independently, although she recognised it as a workable concept and explored the challenges for Fraser’s emancipatory model to overcome fundamental disagreements about who and what is involved to achieve justice. Butler (1998) viewed the domain of identity as central and was critical of this framework since it accentuated the need for economic reform. She claimed that to de-emphasise culture equated to a “resistance to unity” (p. 44). Honneth (2001) was perhaps Fraser’s most vigorous and engaging critic, asserting that recognition was fundamental and that the compartmentalisation of redistribution and recognition created a false distinction. He suggested that the concept of recognition had been reduced to a cultural notion of identity politics that failed to fully grasp the complexities and varied components of recognition. In many respects, Honneth and Fraser were arguing for the same side. Both acknowledged that recognition and rights-based approaches to social justice were essential, as was more just allocation of resources. Honneth, however, asserted that the struggle for redistribution stemmed from a struggle for recognition. He saw maldistribution as indicative of the sociocultural values attributed to certain activities and roles. As such, redistribution would apparently flow from struggles for recognition.
In contrast, Fraser saw it as necessary to explicitly highlight redistribution and the economic aspects of the struggle for social justice. She agreed that recognition and rights-based approaches were essential, but claimed that identity-focused approaches to social justice had the propensity to disregard or diminish the importance of economic aspects. The danger in emphasising the recognition aspect of this struggle was that group identities and stereotypes would be reinforced and that structural change would be avoided through authorities offering up rhetoric and tokenistic opportunities for participation.

While McNay (2008) agreed that a focus solely on recognition was insufficient, he was critical of Fraser and Honneth’s approaches for their lack of acknowledgement of agency, particularly political agency. He asserted that both Fraser and Honneth failed to address the power relationships which shape political and social conflicts and in doing so, notions of participatory parity and recognition were seen to be inadequate.

Fraser’s focus on the economic domain of social justice had been crucial during periods in which identity formed the primary focus of many efforts to overcome discrimination and subordination and the dualism of her model allowed for an interpretation of disparity that was more complex and systemic than that central to identity politics, which revealed the relationships between capitalism (and therefore consumerism) and subordination. While those people experiencing marginalisation may indicate issues of identity and/or localised causes as major influences, participatory parity reveals that:

The economic injustice that the groups in these communities suffer are rooted in the history of the formation of modern global capitalism and its effects in particular places and points in time, causes that are not necessarily transparent to
the sufferers, whose complaints often target more immediately visible and diverse fellow-sufferers (Lovell, 2007, p. 73).

Reflecting on Mick Dodson’s (1993) image of social justice in Australia, it was clear that acknowledgement and even respect in terms of identity and culture did not go far enough to address issues of health and livelihood. At some point, there are real, tangible resources which must be allocated to meet real, tangible needs. Further, Fraser’s work responded to the risk of reification within identity-focused struggles for recognition. The risk was that identity struggles did not always sufficiently recognise the unique and complex nature of the individuals within a group and that the sense of those people as ‘other’ could be reinforced through the group identity.

Fraser’s domains of recognition, redistribution and representation offered a way of ensuring that participation was not diluted into tokenistic seats at a table, compliance or individualistic therapeutic intervention. She reclaimed Marx’s prioritisation of economic power, while acknowledging the value of identity. Obstacles to participation were seen to take cultural, economic and political forms and it was fundamental to this model that efforts to address cultural barriers alone would not lead to change (Fraser, 2008b). All three domains of the parity of participation model were considered important, but the need for redistribution had been emphasised to reposition the political economy as crucial to the social justice agenda. When considering the complexities for establishing a working definition of participation which actually reflects the multifaceted and systemic challenges intrinsic to social justice, it is apparent that the type of dualism (later threefold with the inclusion of representation) inherent in Fraser’s model of participatory parity affords a useful tool for analysing the impact of human service interventions on equality and opportunity. Whether the framework has value as
an operational framework for actually formulating and evaluating policy and practice is, as yet, untested.

Notions of parity and equality were as problematic as participation in many respects, a fact well recognised by Fraser. Who should be equal to whom? What should be equal? Isn’t inequality essential to the functioning of a capitalist society? In *Scales of Justice* Fraser (2008b) explored transnational notions of parity of participation, and in suggesting that bounded polities were insufficient for determining the “who” of social justice, recommended the “all-subjected principle” (p. 65). By this principle, all those who were subject to the governance of a particular structure had rights and obligations of participation. Fraser posited a dialogic approach to addressing and resolving issues of parity of participation, suggesting that it was something that must be determined by the people themselves. As such her work was an invigoration of the democratic ethos of participation.

Theoretically this made sense, but the practicality of such a dialogic forum was more difficult. What would this actually look like and what kind of power and influence could be exerted? Fraser (2008b) warned of the danger of recreating sovereign state models through any attempt to perfectly align counterpublics with state-like powers. In beginning to conceptualise the workings of this dialogic approach, the importance of a deliberative democracy model also became apparent, acknowledging the value of citizen forums and mechanisms to engage in the democratic process beyond voting rights. The suggestion of a dialogic approach also indicated a potential feature of any model of EBP which sought to achieve parity of participation.
Why not social inclusion?

Within Australian social policy, the term ‘social inclusion’ gained popularity in the mid to late 2000s and it provided a framework for the Rudd Labor Government’s federal social and welfare agenda (Australian Government, 2009c; Buckmaster, 2009). Within this agenda, the Australian government prioritised:

- incidence and needs of jobless families with children
- support to children at risk of long term disadvantage
- ensuring programs and services are getting to the right locations, neighbourhoods and communities
- homelessness
- employment for those with a disability or mental illness, and
- closing the gap for Indigenous Australians.

The term social inclusion had its roots in Europe, and gained international prominence through the policies of the Blair Labour Government in the United Kingdom, also known as “third way” politics (Giddens, 2000, p. 3). Social inclusion emphasised participation in terms of taking part in the labour market, with employment conceptualised as the ultimate goal for social policy and for the realisation of economic participation, although it was a policy which attempted to balance economic and social goals. The value of the social inclusion agenda was that it recognised that poverty was not just an income or finance related issue and it acknowledged the diverse ways that people are excluded from full participation in society. However, confusion and ambiguity abounded regarding the definitions and principles underpinning Australian approaches to social inclusion (Long, 2010). While policy pertaining to the national social inclusion agenda tended toward labour-market inclusion, the Australian Social
Inclusion Board (2010) was increasingly emphasising a capabilities approach, defining social inclusion as people having the “resources, opportunities and capabilities they need to … learn … work … engage … have a voice” (p. 15). While promising in its emerging emphasis on diverse and complex arenas of participation, the notion of social inclusion remained contested and ambiguous for the purposes of analysing participatory aspects of human service policy and practice.

The concept was problematic and insufficient for the purposes of this study for a number of reasons. First, the focus on participation as employment created a dichotomy between the employed and the unemployed that failed to recognise the complexities within an individual’s circumstances. Despite the Australian government’s efforts to convey social inclusion as a broad and multifaceted notion of participation, it is apparent that the social inclusion agenda in Australia tends to “prioritise in large part a conception of SE [social exclusion] as unemployment and SI [social inclusion] as workforce participation and maintains a concerning emphasis on economic performance as the driver of the SIA [social inclusion agenda]” (Long, 2010, p. 174). As shown in the following case study chapters, employment may be well down the list of priorities for people facing crisis situations or dealing with multiple, interwoven challenges, such as those implicit in dealing with mental illness or homelessness. While income and economic participation were important and valid components of any framework to enhance equality, there was a redistributive requirement to any social policy that recognised these complexities.

Secondly, social inclusion implied that there was some norm of societal membership in terms of which individuals were either included or excluded. There was a level of compliance required to fit within this norm that could result in a focus on the requirement for individuals to change their behaviour rather than promote structural
change. As will be seen through the analysis of the principle of parity of participation below, the opportunity to participate was considered a more appropriate measure because it allowed the individual to choose whether or not to take part, or which parts of an opportunity to take up.

The literature review revealed the ways in which tools such as EBP had been appropriated to achieve streamlined, outcome-driven practice and policy. The task now is to reappropriate EBP and similar tools to achieve true structural change and genuine participation. Further, the concept of social justice tended to be described as an abstract one, often cited but rarely defined or conceptualised in a tangible sense. Fraser’s (2005) principle of parity of participation proved useful in determining what social justice actually looked like and what the elements were within such a lofty aspiration.

**Theoretical framework for EBP and service-user participation**

The literature review indicated that enhanced participation was an important, but poorly conceptualised and poorly implemented principle for human service delivery in Australia. The review also showed, in Chapter 2, that EBP offered much promise as a tool to improve the accountability and quality of services and policy, but that it had failed to really grasp its place in the social sciences. Following this analysis it was important to consider how these principles and tools could potentially strengthen the model of policy making and service provision in Australia.

The theoretical framework considered how models of practice and policy making could be enhanced through the principles of EBP and parity of participation. Parity of participation referred to a society in which all members had an equal opportunity to take part in the range of activities and to access the range of resources available in that society. It referred to the realisation of equal status for members of a
society in which certain people were not subordinate to others. The elements of recognition, redistribution and representation were used in this framework to encapsulate the complexity and depth of the notion of participation necessary to meet social justice goals. The theoretical framework also considered the strengths of an evidence-based approach, from an individual client level of practice, through to broader notions of evidence-based practice and policy making. EBP’s potential to enhance accountability to the client and service users and to contribute to more transparent decision-making processes was harnessed. Knowledge was conceptualised, not as the domain of academics or other experts, but as a shared capital produced in collaboration with service users and other stakeholders. This theoretical framework provided a starting point for modelling a form of EBP that met social justice goals, and was tested and reformulated as the research progressed.

Figure 3.1 provides a conceptual framework of the way in which EBP could fit with a model of participatory parity, asserting that, if EBP were to be truly effective, it would need to function as something more than a cause and effect type problem-solving tool and would need to be configured in a way that recognised and responded to the related and complex ways in which people were subordinated. As such, the research considered the capacity for EBP in its existing form to meet a social justice agenda and proposed how evidence-based processes, whether EBP or some other incarnation, should be designed to fit within such a framework.
Parity of participation and EBP: Potential roles

The types of participatory roles for service users envisaged in the literature indicated that existing conceptualisations of the role of service users in EBP were at an individual or representative level and located the service user as either demanding or supplying evidence for practice and policy making (Honey, 1999; Nutley, Walter, & Davies, 2007). Based on the analysis of existing literature about service-user participation in general, and service-user participation in EBP or other research-related activities in particular, some options emerged with which to begin conceptualising how this type of theoretical framework could be operationalised, as shown in Table 3.1.
Table 3.1: Roles for service users in EBP

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<tr>
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<th>Individual</th>
<th>Representative</th>
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<tr>
<td><strong>Supply</strong></td>
<td>Service user conducts own research and locates information to guide decisions about treatment and services.</td>
<td>Service users lead, contribute to, or advise conduct of research and dissemination and implementation of research findings. Service-user ideas and experiences considered part of the evidence base.</td>
</tr>
<tr>
<td><strong>Demand</strong></td>
<td>Service user demands evidence from service providers to support individual decision making, or seeks services that implement EBP.</td>
<td>Service users advocate for policy and programs that are supported by evidence, or use evidence to inform and guide advocacy activities.</td>
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The questions that remained unanswered by the literature that this study sought to resolve were:

1. How might EBP activities be undertaken in a way that enhances the opportunity for service users to participate equally and which challenged structures that subordinated vulnerable individuals and groups? The literature demonstrated that the act of participation, or having a representative participate, did not constitute parity of participation and had the potential to be manipulated and reinforce inequality.

2. Did service users consider evidence and processes related to EBP important in determining the quality and appropriateness of services? Did they consider evidence useful in making decisions about treatment and services? What form did information need to take in order for service users to find EBP beneficial and participatory?

3. In what ways could EBP and service-user participation aspire to influence policy and programming and what contribution could be made to improve the conditions of social justice in Australia?
The gaps emerging from a review of service-user participation and EBP literature highlight the need to glean a deeper understanding of the service-users’ perspectives, given that many of the ideas regarding the benefits and outcomes of service-user participation remain untested and that the relationships between participation and EBP have been to this point largely theoretical. As such, the following chapters will seek to examine service user experiences and expectations of human service policy and practice, to determine whether there is a fit between evidence-based modes of working and social justice aspirations.
The literature reviews have thus far revealed the way in which EBP has been conceptualised primarily from the perspective of policy makers and service providers, failing to translate intentions for client centredness into actual practice. Therefore, as a study seeking to refocus debate regarding EBP onto service users, it was important that the methodology afforded opportunities for service users to represent their own views and for ‘lived experience’ to feature centrally as a data source (Turner & Bruner, 1986). Further, the reviews of EBP and participation literature, when considered against the theoretical framework of participatory parity, revealed the failure of existing EBP and participation mechanisms to account for the complex personal and systemic issues and inequalities pertaining to the most marginalised members of the society. This chapter will explain the methodological processes utilised to build an understanding of the Australian human service context in relation to EBP and participation, and of service users’ experiences and perspectives within this context. It describes the challenges for engaging service users in this type of research, strategies adopted to respond to such challenges, and, importantly, the benefits of gleaning the service-user perspective.

The study was premised on there being a need to improve the systems and processes by which services and policies were designed and delivered, and to build the theoretical foundation on which these were based. The research tested the role that EBP and service-user participation could play in this type of reform. This was a new way of looking at policy making and practice. The exploratory, comparative case studies of service-user involvement in human service provision explored the relationship between
EBP and service-user choice in Australian welfare policy. There was little already known about the Australian service-user perspective on EBP and, given the limited implementation of EBP within Australia, it was difficult to measure current practices, attitudes, and knowledge. The study was thus intended as a starting point to identify the options for service-user involvement in EBP and in-depth perceptions of the relationships between evidence and participation.

Philosophers such as Kant and, later, Dilthey have long contemplated distinctions between objective, positivistic and personalised, subjective ways of knowing the world. Dilthey saw that the priority for human sciences was to connect singular, individual lived experiences to broader structures of society (Tool, 2007). In this study the individual experiences of service users, and to a lesser extent service providers, were examined against broader structures through the analysis of public policy. Bruner and Turner (1986), anthropological pioneers in the use of lived experience as method, noted “inevitable gaps between reality, experience and expressions” (p. 6-7). This study did not seek to reflect on gaps between the experiences put forth by research participants and any type of objective reality. Rather, it took the stories and ideas of service users as legitimate and meaningful sources of data from a particular, subjective perspective, necessary to add insight to previous analyses of human services that had tended towards other perspectives (such as researchers, academics and practitioners).

The study was concerned with the ways in which empowerment strategies might play a role in EBP. It considered how these strategies might contribute ultimately to improved ‘outcomes’, particularly good outcomes as perceived by clients or service users. Much prior participatory research had been wary of positivistic-empirical approaches (Baxter, Thorne & Mitchell, 2001; Turner & Beresford, 2005), but this
study recognised the value of systematic, rigorous, empirical approaches and the importance of both quantitative and qualitative methodologies. The goal of the research, however, was not about emancipation or empowerment as an end in itself. Rather, the notion of participatory parity theorised by Fraser (2000, 2005) was used as a framework in which to consider the types of structural reform required and to clarify the aspirations for policy making and practice in relation to service users and social justice.

In-depth interviews with key informants from two case study groups were conducted to examine expectations regarding the use of evidence by social services, to explore the roles which service users perceived for themselves in human service development and delivery, and the benefits and challenges to participatory and evidence-based approaches. The aim was to produce a focus-group tested model for professionals, policy makers, and service users. The methodology was designed such that the research culminated in a model for practice and policy making, which could undergo further empirical testing regarding the effectiveness and impact of service-user participation in EBP processes in future projects.

As indicated by the literature review, the hierarchy of evidence is a fundamental concept within EBP, positing meta-analyses or systematic reviews of randomised controlled trial studies as the highest level of evidence (Gambrill, 2006b; Roberts & Yeager, 2004). However, M.W. Fraser et al. (2009) suggested that, in the early stages of developing an intervention, it could be useful to invert this hierarchy of evidence, and that a randomised controlled trial of the intervention would be suitable only after the program had been developed fully and subjected to broad quantitative and qualitative testing. In this model, “Expert Opinion, including that of Practitioners and Consumers” (Fraser et al., 2009, p. 12) was the first level of evidence gathered to assess the effectiveness of an intervention, after which cross-sectional studies and case reports
could be used. This concept of the inverted hierarchy of evidence was influential on the methodology for the study, which gathered expert opinion, including professional and service-user opinion, as a starting point to understanding the human services practice context. The development of two case studies based on expert opinion and policy analysis, led to a model of evidence-informed practice and policy making. It was, however, beyond the scope of this exploratory study to undertake further empirical testing of the model. The value of the inverted hierarchy of evidence was that the context for the evidence was determined first by gaining the input of those at the coal face or those with the lived experience.

To attain rigour within the methodology for this qualitative research project, frameworks and hierarchies for generating, analysing, and reporting qualitative data were important. A case study approach was employed, including methods of policy analysis, in-depth interviewing, and focus group testing, with consistent and thorough data analysis protocols applied to draw out key themes and inform recommendations.

Daly et al. (2007) used the hierarchy of evidence as a format for approaching qualitative research. They described a hierarchy of evidence-for-practice in qualitative research, which posited generalisable studies as the gold standard for qualitative research. Their approach aimed to build on the strengths of qualitative research, such as its flexibility and ability to gather in-depth knowledge, rather than to try and fit these approaches into a positivistic-empirical mould. Following this approach, the explicit reporting of consistent and clear data collection and analysis protocols was important to the study. It was determined that sample size did not need to be large and objective, but strategic, purposive and of a size which allowed the full picture of experiences to emerge. The study recognised that generalisability could be problematic for the complex
social and welfare issues addressed by human services and the unique conditions within each of the case study settings.

**Research process**

The stages of the research process reflected the various levels of policy making and practice that needed to be examined in order to provide a full picture, in accordance with the case study methodology. The first stage examined the broad context for social service delivery and policy making in Australia and located EBP and service user participation within this setting. A review of international and national literature as well as a broad examination of policy making within social services in Australia provided insight into the key issues and debates. The survey of Australian Association of Social Workers (AASW) members regarding their knowledge and experiences of EBP, conducted for the Australian Research Council, contributed to a deeper understanding of existing practice, given the fairly limited base of Australian literature in this area. The second stage entailed the collection of the core data set, which consisted primarily of in-depth interviews with service users from each case study, substantiated by a sample of interviews with service providers and an analysis of key policy documents specific to each case study area. The analysis of these core data sources was conducted during the third stage, at which preliminary findings and recommendations were drawn. To test the workability, accuracy and relevance of these findings and recommendations a fourth stage of focus group testing and dissemination was completed. The key steps and methods completed to achieve the research aims are summarised in Table 4.1.
Table 4.1: The research process

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<th>STAGES</th>
<th>METHODS</th>
<th>STEPS</th>
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<td><strong>STAGE 1: SETTING THE CONTEXT</strong></td>
<td>1. Literature review</td>
<td>Step 1: Conduct a literature review of:</td>
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<td></td>
<td>2. Review policy context</td>
<td>1. The contemporary social services context in Australia.</td>
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<td></td>
<td>3. ARC EBP survey</td>
<td>2. EBP and service-user participation to identify and examine the range of options for service-user involvement in EBP processes.</td>
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<td>Step 2: Conduct a broad review of the policy environment for human services in Australia</td>
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<td>Step 3: Select case studies</td>
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<td>Step 4: Draw on findings from ARC EBP survey</td>
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<tr>
<td><strong>STAGE 2: DATA COLLECTION</strong></td>
<td>1. Case Studies:</td>
<td>Step 1: Identify and collate key data sources pertaining to each case study, including policy documents, relevant literature, prior research</td>
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<td></td>
<td>a. Homelessness</td>
<td>Step 2: Conduct in-depth interviews</td>
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<td>b. Mental health</td>
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<td></td>
<td>2. In-depth interviews</td>
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<tr>
<td><strong>STAGE 3: DATA ANALYSIS</strong></td>
<td>1. Thematic content analysis</td>
<td>Step 1: Conduct thematic content analysis of policy documents</td>
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<td></td>
<td></td>
<td>Step 2: Openly code interview transcripts</td>
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<td></td>
<td></td>
<td>Step 3: Determine key categories and themes</td>
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<td></td>
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<td>Step 4: Consider key categories and themes in relation to theoretical framework to develop preliminary summary of findings</td>
</tr>
<tr>
<td><strong>STAGE 4: FEEDBACK AND DISSEMINATION</strong></td>
<td>1. Focus groups</td>
<td>Step 1: Send out preliminary summary of findings to participants</td>
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<td></td>
<td>2. Dissemination</td>
<td>Step 2: Conduct focus group testing of guidelines and model</td>
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<td>Step 3: Analyse focus group feedback against proposed model</td>
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<td>Step 4: Prepare plain language summary of findings</td>
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<td>Step 5: Disseminate findings to all participants and relevant stakeholders (written and verbal presentations)</td>
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The aims of the study

The theory of parity of participation, discussed in Chapter 3, suggested that it was crucial to sociological research to examine the ways in which members of society were excluded or their full participation was inhibited in cultural, economic, and political terms (Fraser, 2005, 2008a, 2008b). Further, it suggested that potential policies or actions to remedy social injustice should be considered in terms of their effect on redistribution, recognition or representation and examined to ensure that further inequality or disadvantage was not generated. The research considered the ways in which current models of policy making and service provision within the homelessness and mental health sectors in NSW either inhibited or enhanced the participation of people who had experienced homelessness or mental illness respectively and the potential, or otherwise, for evidence-based approaches to policy making and service provision to enhance parity of participation. To this end, the study explored service users’ needs regarding policy making and service delivery and the ways in which service-user groups might play a part in improving the use of evidence in social services in Australia. The research aimed to:

1. determine the form EBP should take in order to achieve improved parity of participation
2. determine the value of evidence to service users and their expectations about how evidence should inform human service provision, policy making, and practice
3. identify existing and potential roles for service users in EBP, and
4. develop a model of EBP that fits within the parity of participation framework and considers the inclusion of service users.
Key research questions

Thus the following research questions were asked.

1. What were the barriers and opportunities to creating more equal participation of service users?
2. What role could EBP play in overcoming these barriers or building upon these opportunities?
3. Did service users have an expectation that practice and policy was informed by evidence?
4. What value or importance did service users attribute to evidence, including its relationship to decision making?
5. How did service users expect policy makers and practitioners to engage with them on the development, dissemination, and implementation of evidence?
6. What types of expertise were valued?
7. What value was placed on service-user involvement in practice and policy making at individual and representative levels?
8. How were service users involved in practice and policy making at individual and representative levels?
9. Were practices and policies developed and implemented in a way transparent to service users?
10. To what extent, and in what ways, were practitioners and policy makers accountable to service users?
11. Was there a significant difference in the way that service providers and service users viewed the value and use of evidence?
12. Could service-user participation support EBP implementation and, if so, how?
13. What factors or dynamics determined the demand for EBP by service users?

Research methods

Literature review

The findings of the literature review process were presented in Chapters 2 and 3, in two sections to reflect the discrete fields being examined in the study, namely EBP and service-user participation. A literature review of each area concentrated on specific themes to determine the context for the study, highlighted key theoretical issues, and presented relevant arguments that acted as functional points for the modelling process. Literature was predominantly sourced through electronic databases, including JSTOR, Informit, SAGE Journals Online, Wiley Online Library, and EBSO Megafile Premier, as well as internet Google and Google scholar searches. Reference lists of key articles were also used to identify further literature.

Within the area of EBP literature was selected for review based on its relevance and significance to contemporary debates about the implementation and importance of EBP and, more specifically, for its discussion regarding the client, consumer, or service-user role in EBP. Search terms to locate literature on electronic databases and the internet in the first instance included: (i) evidence OR evidence-based practice OR evidence-based policy making OR evidence-based practice and policymaking; (ii) participation OR collaboration OR social OR welfare OR knowledge.

Within the area of service-user participation, literature was selected for review where it made a significant and original contribution to contemporary understandings and definitions of service-user participation. Search terms to locate literature in the first instance included: (i) participation OR involvement OR collaboration; (ii) service-user
OR service user OR consumer OR user OR survivor; (iii) social justice OR parity of participation OR citizenship OR social inclusion. Included literature examined the relationship between participation and research or evidence-generation processes, demonstrated the relevance of participation as a tool to influence decision making and policymaking, or directly examined the relationship between EBP and service-user participation.

The reviews focused predominantly on literature relating to human or social service delivery but also ventured into related fields, such as medicine and allied sciences where there were findings on service-user participation and EBP, which were influential in or applicable to the social sciences. In addition to these online and electronic database searches, there were a number of resource libraries citing policy and literature references available through organisations and institutes working in the areas of participation and EBP, including the UK Social Care Institute for Excellence (www.scie.org.uk), the Cochrane Collaboration (www.cochrane.org), the Campbell Collaboration (www.campbellcollaboration.org) and the Health Issues Centre (www.healthissuescentre.org.au). Literature was also sourced through discussions with academics working in the areas of EBP and service-user participation in Australia and the United Kingdom and through conferences, including the Consumers Reforming Health conference and Social Participation: Knowledge, Policy and Practice conference.

The literature review was significant as a method for examining the background to the key issues and establishing the current context, and also for revealing potential case study domains. By examining the Australian literature regarding policy and practice in relation to service-user participation and EBP, sectors in which EBP and service-user participation were either established or emerging were identified.
**Survey**

The research findings were informed by a quantitative survey of social workers in Australia funded by the Australian Research Council (ARC) which was undertaken through the Research Institute for Social Inclusion and Wellbeing (RISIW) at the University of Newcastle. While I was a member of the steering committee on this project, it was not a core part of the PhD research. However, this research on the implementation of EBP by social workers provided a useful source of information regarding human service practice and is reported briefly to provide a context for the present study. The survey, disseminated through the AASW, explored barriers and enablers to EBP implementation, social workers’ understandings of EBP and the relevance of EBP to professional practice. Participants completed an online survey which included a series of open-ended and closed-ended questions, which were analysed to determine key trends and themes. The survey also included two key questions relevant to this study about social workers’ perspectives on the value of EBP to their clients and about the level and type of information provided by social workers to support their clients in making informed decisions about treatments and programs.

**Case study approach**

Yin (2009) suggested the case study approach is useful for in-depth research which seeks to determine the “how” and “why” of social phenomena, where no control over behavioural events is required, where the focus is on “contemporary events” and where it is important to examine the situation within context (p. 8). This study sought to examine the experiences of service users within the contemporary context of Australian human service policy and implementation, exploring how EBP and participation impacted on service users and why service users engaged in, or disengaged from,
particular elements of EBP and participation. A multiple case design sought to contrast two comparable groups of service users using one theoretical framework, but it is important to note the limitations of generalisability that apply to such case study methodology. The study deliberately examined service user groups likely to be amongst the more marginalised within Australian human services, and in doing so offered interpretations and tested theoretical models that may have resonance amongst other human service sectors, especially those which target marginalised groups or individuals. However, it was not intended as a representative sample or to “enumerate frequencies” (Yin, 2009, p. 15).

The human services sector in Australia is diverse with contested and often unclear delineation between other sectors, such as health, welfare and education. To narrow the focus of the research and support an in-depth analysis, the two specific human service areas of mental health and homelessness were selected. Multiple information sources allowed for a process of triangulation, to determine where evidence was convergent or contradictory (Yin, 2012). The key information sources to inform the analysis of each case study were:

1. policy documents and reports, specifically those of the New South Wales and federal governments
2. review that focused only on literature related specifically to service-user participation or EBP within each of the case study areas
3. in-depth interviews with users of mental health and homelessness services
4. in-depth interviews with service providers and policy makers in the areas of mental health and homelessness, and
5. focus group testing of initial findings with service user representatives from each sector.
The two case studies were purposefully selected based on the following criteria, determined through the literature review process and a preliminary analysis of policy documents. They demonstrated emerging or existing:

1. processes for service-user participation, and
2. interest in EBP.

A purposive sampling strategy was adopted, with the intention of focusing on “information-rich cases” (Liamputtong, 2009, p. 11) which provided insight into a little-known subject. The case studies of homelessness and mental health were selected for their potential as highly informative cases given the existing and developing levels of EBP and service-user participation. These case studies provided useful contrasts and comparisons, being closely related areas of service provision, but with quite different approaches to practice and engagement of service users.

Stake (2005) claimed that the “Case study is not a methodological choice, but a choice of what is to be studied” (p. 443). He proposed a number of stages to the case study approach as follows:

1. Bounding the case, conceptualising the object of study.
2. Selecting phenomena, themes or issues (research questions to emphasize).
3. Seeking patterns of data to develop the issues.
4. Triangulating key observations and bases for interpretation.
5. Selecting alternative interpretations to pursue.
6. Developing assertions or generalisations about the case (Stake, 2005, pp. 459-60).

There were a range of methods within the case study approach which could be used to draw out both the commonalities and unique features of the case. This project took the form of a multiple or comparative case study, in which a number of cases were
drawn upon to examine and demonstrate various aspects and manifestations of the interaction between EBP and service-user participation. As per the collective instrumental case study approach, the findings of the research could not be generalised or aggregated across cases, but were presented as individual, bounded examples. The findings from each case were contrasted and compared, but retained their status as unique cases.

It was fundamental to the case study to determine the boundaries of the cases under enquiry in accordance with analysis of a bounded system, central to the case study approach (Liamputtong, 2009). For the purpose of this study, the two cases under enquiry included people with experience of homelessness and mental health who had participated in either consumer representation or advocacy activities. While these groups of individuals were not the only source of data and information for the research, they were the cases to which all other sources of data related. In-depth interviews with members of the case study groups were a central method for the research, and the findings from these interviews were triangulated through the collection of data from qualitative interviews with service providers and policy makers, which tested for tension between service user and service provider understanding and through policy analysis to identify the context and frameworks in which the cases operated.
Policy analysis

Policy making is a reflection and a determinant of the context in which practice and service provision occur. Pawson (2006) proposed a critique of the current approach to evidence-based policy making that was fundamentally concerned with the inability of processes, such as systematic reviewing, to account for the complexities and contextual intricacies of settings to which the evidence must be transferred. His analysis spoke to the crucial and often convoluted relationship between practice and policy making which has tended to be oversimplified in most approaches to EBP. He noted that “policy is delivered through active interventions to active subjects” (Pawson, 2006, p. 27) and that the domains of policy making and practice were inextricably linked. Ultimately, policy ambitions could not be realised without consideration of the complex and often highly individualised circumstances of the end user. For this reason, it was important to the
research methodology to analyse the policy context in which the two case studies
operated, to examine the potential for a participatory model of EBP that considered the
cycle from policy, to practice, to service usage.

The analysis of the policies relevant to each case study was crucial to identifying
the forces which acted upon models of funding, priority areas, program choices, and
strategic approaches. It was also important as an initial step in considering the
relationship between service users and high-level decision making and the actual
potential for the findings of the research to feed upwards into the policy-making cycle.

A thematic content analysis methodology was adopted to examine the existing
and proposed strategies related to a participatory model of evidence-informed practice
and policy making in the homelessness and mental health sectors in Australia. Key
policy documents were collated, through searches of federal, state and local government
databases, as well as by using information clearinghouses and databases specific to each
of the case study areas. These searches sought to identify the major policies and
strategies regarding homelessness and mental health at a federal and state level,
particularly white papers, strategies, and action plans. They also sought to identify
policy documents related to each case study which focused specifically on participation
or evidence and research, such as guidelines and handbooks on participation and
government agendas and funding allocations regarding research activities. For the
homelessness case study, the Homelessness Information Clearinghouse was a key
source of information, providing regular updates on government policy, community
sector activities, reports, and media releases (National Homelessness Information
Clearinghouse, 2010).

Policy documents, reports, and strategy documents were analysed with
consideration to a series of key questions. At the first stage, a basic content analysis was
conducted to identify incidence and occurrence of key terms related to EBP and service-
user participation, as per the search terms below. A process of open coding was then
conducted to identify relevant themes and highlight key parts of texts to which a deeper
thematic analysis was applied, which examined how each policy document related to
the categories of enquiry and key research questions shown in Table 4.2.

Table 4.2: Criteria for policy analysis

<table>
<thead>
<tr>
<th>Key questions</th>
<th>Key terms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Evidence-based practice</strong></td>
<td>Evidence, evidence base, evidence-based, evidence-based practice, evidence-based policy making</td>
</tr>
<tr>
<td>1. What claims were made regarding the extent to which policy was informed by evidence?</td>
<td>Research, data, quantify, qualify, information source, external source</td>
</tr>
<tr>
<td>2. To what extent did policy frameworks encourage and enable EBP at a practice and service delivery level?</td>
<td>Funding criteria, best practice, guidelines, practice guidelines</td>
</tr>
<tr>
<td><strong>Service-user participation</strong></td>
<td>Service user, consumer, user, survivor, client, advocate, representative</td>
</tr>
<tr>
<td>1. What claims were made regarding the extent to which service-user participation factored in the policy making process?</td>
<td>Involvement, participation, input, consultation, collaboration, partnership, empowerment</td>
</tr>
<tr>
<td>2. To what extent did policy frameworks encourage and enable service-user participation at a practice and service delivery level?</td>
<td>Social inclusion, social exclusion, social justice, citizen</td>
</tr>
</tbody>
</table>

Once key themes had been identified within the policy documents, these were
considered against the theoretical framework, with respect to parity of participation and
EBP, to analyse the existing and potential opportunities for an evidence-informed model
of practice and policy making.

The policy analysis provided an important context against which to analyse the
data collected through the interviews and focus groups. The policy documents reflected
the intentions and priorities of government, whereas the perceptions and experiences of
the interviewees represented the way in which this policy was realised or in which it failed to achieve its intended purpose.

**In-depth interviews**

The research methodology faced one of the key limitations of all consumer or service-user involvement strategies, that “there is no such thing as a single consumer voice” (Epstein & Olsen, 1998). Those who accessed human services were not homogenous groups with identical needs and experiences simply because they fitted broad categories, such as ‘person with experience of homelessness’ or ‘mental health consumer’. The study acknowledged the limitations involved in attempting to represent the perspectives and experiences of a group as broad and poorly defined as service users. Two key limitations and approaches assisted in refining the focus of the study and offering a defined and workable focus for developing the initial findings in this new area of research. The first was the case study approach itself, which ensured that the focus of enquiry was contained within a specific service sector and related to a specific social or welfare experience. The second was the focus of the study with those people who had a relationship with a consumer advocacy or service user representative organisation.

**Selection of participants**

The selection of service users with active roles as consumer advocates or members of service user representative bodies was a deliberate strategy which acknowledged the heterogeneity of service users and the challenges of representation. The process of accessing research participants, particularly socially excluded and difficult-to-reach groups, via people or agencies with existing and established relationships with the socially excluded people is often referred to as “gatekeeping” (Emmel, Hughes,
Greenhalgh, & Sales, 2007, para. 4.1). In this study staff working with the service-user groups acted as gatekeepers to potential research participants. This strategy is seen to present limitations potentially in terms of introducing the bias of those gatekeepers and engaging with power relationships that may exist between gatekeepers and socially excluded people. In the mental health case study this was not problematic, because the role of the gatekeeper agencies was merely transmission of information via existing modes of communication, and service users within fairly large networks were able to self-nominate directly to the researcher. It was already a recognised criterion for participation that the service users have some degree (however small) of affiliation with a representative organisation or forum, so it was appropriate to recruit via such organisations and forums. However, given the small numbers of individuals identifiable as service-user representatives in the homeless sector, the role of the gatekeepers was more pronounced and the staff in the agencies which supported service-user groups played a more pronounced role in recruiting participants. This was offset by strategies such as the researcher speaking directly with service users at their meetings prior to the study such that the group had the opportunity to consider its participation and ensuring that actual interviews were private interactions between the researcher and service user.

The method of participant selection sought not to offer a perspective of all service users, but instead looked at service users with the common feature of being representatives, of speaking on behalf of themselves and or others, or participating at some level in the shared experience of being a service user. Generally representatives or advocates had high levels of confidence, support and skills and participants were, therefore, not necessarily representative of all service users. It should be noted, though, that participants’ levels of involvement and activity varied significantly. Some were in paid, professional service-user leadership roles, particularly in the mental health case
study. Others identified as advocates working through informal or personal channels. Some were more passive members of organisations, merely receiving information or support. It was considered that these service-user representatives were able to provide insight based on their own and, to a limited extent, their peers’ experiences. Service-user representatives, as individuals, given their involvement at the interface between policy making, service provision, and service use, were also considered an important starting point for any innovations regarding service-user participation and EBP.

In-depth interviews were conducted with individual participants, usually face-to-face, but also by telephone when it was not possible to meet in person due to practical and logistical challenges. It was considered appropriate to use the telephone to conduct interviews given that the subject matter was not likely to evoke deeply personal or challenging responses from participants and, in some situations, was even preferred by the participants because they felt more comfortable expressing their ideas in this forum. Interviews were informal and semi-structured. An interview guide (see Appendix A: *Script for semi-structured interviews*) was used, with deviations as required, which covered the following key points:

1. Understanding of the terms ‘evidence’ and ‘Evidence-based Practice’.
2. Sources and types of information used to make decisions or build knowledge about issues and available services and extent to which service users undertook their own research to build their knowledge base.
3. Types of human services used or provided, extent to which these were considered evidence-based, and types of information and evidence available through these services.
4. Extent to which service users made active choices about service use and preferred mechanisms to support decision making.
5. Experiences as a service user representative or advocate.
6. Aspirations for service-user participation.
7.Extent to which evidence influenced service-user participation activities.
8. Level of service-user input to policy making.
9. Experiences in research or other activities that build the evidence-base and interest in this type of activity.
10. Expertise and the value of service-user knowledge, experience and opinion.

Identification and recruitment of service-users

A search of the literature and key policy documents revealed prominent consumer advocacy groups operating within NSW. These groups were contacted to introduce the research and discuss the most appropriate method for recruiting potential participants.
Table 4.3 Numbers and pseudonyms of research participants

<table>
<thead>
<tr>
<th>Case study</th>
<th>Service users interviewed</th>
<th>Service users in focus groups</th>
<th>Service providers interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homelessness</td>
<td>Total = 11</td>
<td>Total = 3 (over 2 sessions)</td>
<td>Total = 5</td>
</tr>
<tr>
<td></td>
<td>Melanie</td>
<td>Steve</td>
<td>Tim</td>
</tr>
<tr>
<td></td>
<td>Steve</td>
<td>Laura</td>
<td>Pam</td>
</tr>
<tr>
<td></td>
<td>Laura</td>
<td>Sue</td>
<td>Christine</td>
</tr>
<tr>
<td></td>
<td>Paul</td>
<td>Jasmine</td>
<td>John</td>
</tr>
<tr>
<td></td>
<td>Jane</td>
<td>Greg</td>
<td>Sylvia</td>
</tr>
<tr>
<td></td>
<td>Greg</td>
<td>Rodney</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Isabelle</td>
<td>Penny</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Penny</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health</td>
<td>Total = 11</td>
<td>Total = 4 (over 2 sessions)</td>
<td>Total = 6</td>
</tr>
<tr>
<td></td>
<td>Sarah</td>
<td>Tara</td>
<td>Cara</td>
</tr>
<tr>
<td></td>
<td>Martha</td>
<td>Luke</td>
<td>Samantha</td>
</tr>
<tr>
<td></td>
<td>Tara</td>
<td>Claire</td>
<td>Jacki</td>
</tr>
<tr>
<td></td>
<td>Luke</td>
<td>Greta</td>
<td>Brenda</td>
</tr>
<tr>
<td></td>
<td>Claire</td>
<td>Tracey</td>
<td>Dawn</td>
</tr>
<tr>
<td></td>
<td>Greta</td>
<td>Elizabeth</td>
<td>Fiona</td>
</tr>
<tr>
<td></td>
<td>Tracey</td>
<td>Amanda</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Elizabeth</td>
<td>Wendy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amanda</td>
<td>Brian</td>
<td></td>
</tr>
</tbody>
</table>

**Homelessness case study**

For the homelessness case study, service-user groups were initially identified using resources such as the Homelessness Information Clearinghouse. Written invitations were extended to the identified service-user groups and for those situated in NSW, the researcher attended one of their regular meetings to discuss the project and where the group agreed to offer its support, individual members were then able to consent as appropriate. Some service users located interstate were invited to participate because service-user groups had been established for longer periods in other states and they were able therefore to provide a more long-term perspective. For these people written materials were disseminated via staff at organisations supporting the service-user
groups and members had the option to self-nominate to participate. It should be noted that even though service users agreed as groups to participate in the research, not all members of all groups were willing or able to take part in interviews. Interviews with service users who had experience of homelessness were also conducted with a sample of people outside formal service-user groups, who were identified by service providers and other service users as advocates and who had ad hoc roles as representatives and participants in various projects with various agencies. In such cases the staff member who had identified the person acted as a gatekeeper and passed on research information to the individual, who was then directly contacted by the researcher if interested in participation.

**Mental health case study**

The process of recruiting service-user interviewees for the mental health case study differed a little, due to the greater number of service-user groups in this area and the different structures and size of the consumer advocacy groups. Two different service-user groups from within NSW, working in areas such as policy development, advocacy and peer support, were identified and staff members from these groups were contacted to discuss options and strategies for the recruitment of mental health service users. Each organisation placed notices in online and hardcopy newsletters and bulletins, inviting interested participants to contact the researcher to register their interest. They then received a copy of the information statement and consent form. The interviewer arranged either a face-to-face or telephone interview directly with the participant as appropriate. Consumer consultants employed through regional health services were also directly invited to participate in interviews as key consumer representatives within one of the more systematic methods of participation.
Identification and recruitment of service providers and policy makers

Homelessness case study

For the homelessness case study, service providers and policy makers were approached through homelessness interagency networks in the Sydney and Hunter regions. These informal networks of agencies were involved in the delivery of services or the making of policy related to homelessness and came together for bimonthly network meetings. The researcher attended the network meeting and also electronically distributed the information statement to network members, who were then able to self-nominate. A number of agencies were also targeted directly, with the researcher providing a written invitation to participate with a copy of the information statement and consent form. These agencies were targeted because discussions with service users and other service providers indicated that they played a central role in shaping the policy and practice regarding homelessness prevention and intervention. It should be noted that not all agencies directly targeted responded to the invitation and a number declined to participate. Agencies providing coordination and support to service-user groups were also approached to participate in interviews, given their knowledge and experience of participatory processes in the area of homelessness.

Mental health case study

For the mental health case study, service providers were identified through interviews with participants and analysis of key policy documents that highlighted the types of services users considered relevant to this study. The researcher then sent invitations and
information packages inviting these organisations to participate and scheduled interviews as appropriate.

**Data analysis**

In-depth interviews were recorded and transcribed and then a thematic content analysis was conducted of the transcribed interviews to draw out key concepts and themes in relation to the theoretical framework, with reference to parity of participation, service-user participation, and EBP. The computer assisted qualitative data analysis package NVivo was used as a tool to aid the process.

Strauss and Corbin (2008) described a data analysis process called “open coding”, which was the methodology applied to this data. The key concepts within the data were initially labelled or named through a detailed analysis of each section of the transcript. Through this process, the data was open to wide and diverse meanings and interpretations and was examined in a systematic way to refine it into relevant and insightful categories. In accordance with Strauss and Corbin’s (2008) emphasis on context to inform the nature of analysis and the way in which concepts were labelled or described, this study drew heavily on the literature on EBP and service-user participation in the coding and categorising process as the purpose was to test and strengthen the understanding of these principles. The theoretical framework (see Figure 3.1, Chapter 3) and the concepts of parity of participation were also important in suggesting the context and, therefore, in determining categories. Incidence and nature of these concepts were compared and contrasted across different data sources and categorised. For example, a number of interviewees referred to experiences of stigma, discrimination, and stereotyping. The category ‘misrecognition’ was applied to this data to reflect the relationship between the interviewee’s experiences and ideas and Fraser’s
(2000, 2008a, 2008b) framework of parity of participation that shaped the analysis. Appendix B: Coding Summary shows the various codes and categories that were drawn from this process and which shaped the data analysis process.

**Focus groups**

After the preliminary analysis of key policy documents and qualitative interviews was completed, key themes emerged. By considering the themes in relation to existing literature, recommendations about a participatory model of evidence-informed practice and policy making could be made. Initial findings were formulated into a summary of key ideas to support a model of evidence-informed practice and policy making that enhanced parity of participation of service users.

The in-depth qualitative interviews provided an opportunity to probe deeply into individual perceptions and experiences regarding service use, participation, and decision making. However, the process of analysis and interpretation resulted in themes, guidelines, and a practice and policy making model which required clarification and input from key informants to test its workability and potential effectiveness. Individual interviews also failed to account for the type of “interactional dynamics” (Kamberelis & Dimitriadis, 2005, p. 902) that were a very real part of the way in which policy and practice was implemented. Kamberelis and Dimitriadis (2005) suggested that focus groups could be a means to democratise the research process by decentralising the role of the researcher and allowing participants to engage with each other through a dialogic process that could lead to more open and lively discussion and result in a more collaborative outcome. It was intended that, by feeding the initial findings back into the focus group setting, an opportunity to develop a model which was workable in the interactive world of human service provision and one which was considered to reflect
accurately the perceptions and expectations of service users would be possible. This was achieved to a moderate extent, as those service users who were willing and able to participate provided verification of the accuracy and workability of the preliminary findings and recommendations, and were able to elaborate on themes that had emerged during the research process. The focus group process was important as a way to test how the researcher had interpreted the data and to ensure that, in line with participatory modes of working, service users had the opportunity to gain feedback and to provide ongoing input to the project.

Service-user participants in the initial interviews were invited to participate in focus groups of up to seven people. Each focus group was categorised according to the case study of homelessness or mental health. Additional participants were also invited to the focus group by placing notices in the newsletters and bulletins, and through reengaging with the gatekeepers at organisations working with service-user groups. Two new participants who had not previously taken part in the interviews, one in each of the mental health and homelessness case studies, were recruited for the focus groups. This afforded additional anonymity to contributions made through the initial in-depth interview process, as participants in the focus group were not made aware of who had and had not participated in interviews. The focus group participants were provided a plain language summary of the key themes prior to the session. These were also presented verbally at the commencement of the session. Participants were asked to comment on whether the findings reflected their experiences, whether they considered that the guidelines were workable, and whether they believed that the guidelines would support an improved model of practice and policy making. Data from the focus groups were analysed to identify significant and recurrent feedback. Following the focus groups, the key themes and guidelines were revised and reworked accordingly.
Participation in the focus groups was not nearly as strong as in the in-depth interviews and numbers were relatively small. Three key reasons for the lower numbers of participants in the focus groups were ascertained through discussion with gatekeepers, those service users who did attend, and service users who expressed interest but were unable to attend. First, it was logistically more difficult to coordinate groups of people to attend one location at one set time. Whereas in the interview process the researcher was able to coordinate flexibly with the availability of the participants and travel to meet them at convenient locations or by telephone interview, for focus groups this was more difficult. Secondly, service users may have felt their contribution to the research was more anonymous and private within the interview setting and some were not comfortable discussing the research topics alongside other service users. Thirdly, some of the service users who had the capacity and availability to participate in the early stages of the project may have experienced significant changes in their circumstances between the interview and focus group stages of the research (a period of up to 18 months), such as moving, gaining employment, becoming unwell or changing family responsibilities. This reflects an important finding of the study regarding the dynamic and fluctuating nature of capacity and context for users of homelessness and mental health services. Despite the limited numbers of participants in focus groups, participants were active and provided significant feedback and input regarding the preliminary findings indicating that for some, the focus group environment was appropriate. The challenges for conducting focus groups were an important contributor to the research findings because they are indicative of the challenges for engaging marginalised service users in evidence-based processes, iterating the need for multi-faceted, flexible and responsive modes of engagement.
Each focus group was recorded, transcribed and analysed within NVivo using the coding structure established during the analysis of in-depth interview data. Notes were taken during focus groups to ensure recorded quotes could be accurately attributed to the speaker. The emphasis on the analysis here was to test the data from the focus groups against the collated data from the in-depth interviews and the preliminary findings.

**Dissemination**

A summary of research findings was disseminated widely to ensure participants received feedback about the outcomes of their participation and to recognise the interest of participants in developing participatory modes of EBP (see Appendix C: *Research summary disseminated to participants*). The summary was distributed to service-user participants directly where email and mail addresses were available and via gatekeepers where this was not possible. It was distributed to service provider participants directly via email and/or mail, as well as through interagency networks. Research participants were also offered the opportunity to discuss the findings directly with the researcher (especially important for those with limited literacy skills), or to have presentations made to their groups or workplaces.

**Research ethics**

This research, as with most research in social policy, social work, and welfare, was motivated by a desire to contribute to improved policy making and practice that could ultimately, in some small way, improve people’s lives. There was an underlying imperative to this type of research that it be conducted and reported in an ethical way which considered the social responsibility of such a task (Neuman, 2006; Padgett,
2008). Given the focus of the research on enhancing people’s participation in a genuine and meaningful way, it was essential that the methodologies reflected the values of equality, respect, accountability, compassion, and fairness. The people who participated in each case study had all encountered experiences of being marginalised and excluded from full participation in society and it was, therefore, important that participants were afforded a clear choice in how they described their experiences and ideas, that they determined the extent to which they participated in the research, and that their contributions were shown to be valued.

The University of Newcastle had policies and protocols in place guiding all research undertaken through the institution (The University of Newcastle, 2010). This project was subject to approval from the University of Newcastle Human Research Ethics Committee under Level Three Full Review, specifically because of its inclusion of people with experience of mental health issues as research participants. Their perceived vulnerability and potential need for additional support meant that the most rigorous level of assessment applied. Approval for this project was provided on 19 August 2009 under Reference No. H-2009-0233.

There were a number of ethical considerations to the project that influenced the research methodology. As indicated by the literature review, there was a recognised concern that often service-user participation practices had been poorly implemented and tokenistic and, as such, this research risked being perceived as yet another tokenistic or doomed-to-failure effort (Beresford & Branfield, 2006; Braye & Preston-Shoot, 2005; Lindow, 1999; Melville, 2008). To mitigate this, it was important that the input of service users was the central source of data, recognising the value of their lived experience input. However, the research method was not participant-led or participant-
driven, even though these types of models of research were considered and analysed within the study content.

Service-user participants were provided a gift voucher of their choice in recognition of the value of their time and contribution and were afforded the opportunity to ask questions and view the interview guide prior to participation. Most importantly, the focus group process afforded service-user participants the opportunity to have genuine input in the final recommendations and take an active role in shaping the way the research product looked and would be utilised.

The participants in both case studies continued to face a diverse range of personal challenges and many were cycling continually through periods of crisis relating to housing status, mental health, personal relationships, financial status, and other such factors. The research approach was sensitive to this situation and afforded flexibility to participants to schedule interviews and focus groups at suitable times. However, the researcher also acknowledged that people in crisis had a crucial perspective to offer and it was the participant’s decision as to whether they felt comfortable and able to participate at a given time. It should be noted that most participants were in relatively stable circumstances at the time of the interview, a fact which was highly relevant to the overall findings in regard to decision making, vulnerability, crisis, and empowerment. The research found that parity of participation was more compromised in times of crisis.

Because service-user participants in each case study were recruited primarily through service-user representative and advocacy bodies, they were already connected with support mechanisms and resources. Service-user interviewees conveyed enthusiasm for the research process, suggesting that they saw their participation as an opportunity to have a stronger voice and contribute to further policy and practice
reform. All participants completed a consent form and were provided an information statement outlining the research, their responsibilities, and the researcher’s responsibilities (see Appendix D: Participant information statements and Appendix E: Participant consent form). They were both “informed and informing” (Fine, Weis, Weseen, & Wong, 2000, p. 115), aware of their role in the research project, and generally enthusiastic to use the research process as an opportunity to voice their ideas and opinions relating closely to their existing roles as consumer advocates.

Participants in the research talked consistently about the way that they valued their own stories, experiences, and ideas and the importance of this information being used to help others. Tara (mental health service user) stated that “…I know that what I have learnt is useful and I want to share that”. Steve (homelessness service user) stated that “…I would love to be able to utilise those skills that I’ve used, to help other people and to help services help other people”. For many this was a significant factor in their decision to participate in the research project. As such it was important that feedback about the research outcomes was provided to participants, via focus groups, presentations and research summaries.

I considered it a privilege to have people share their ideas and stories regarding service use and this shaped the interactions between the researcher and the research participants. Confidentiality and privacy were essential. This was part of the reason that in-depth interviews were the method of choice for gleaning individual input so that stories could be shared in a private and comfortable environment. Focus groups were only considered appropriate as a mechanism for feedback and more general discussion. During the transcription of interviews and focus groups, all identifying information was coded to protect privacy and pseudonyms were provided for all participants. Hard-copy research data and related sensitive materials were stored securely in locked facilities on
the university’s premises and electronic data was de-identified and stored within password protected, secure devices. All participants were informed that they could withdraw from the project at any time, could review transcripts of their interview, and make changes where they wished to do so, or elect to exclude their contribution from the project entirely. In this way the research attempted to reflect the value of the contributions by individual participants by representing the data in a fair and accurate manner in which the service user’s input was the central focus of analysis.

**An exploratory starting point**

The methodology for the research was shaped by the purpose of improving policy making and practice within the human service sector and the theoretical influence of parity of participation. It sought to contribute a new perspective to the debate on EBP and to ensure that the values and needs of service users were reflected in innovations to the design and delivery of human services. A logical and systematic research process was established that reflected M. W. Fraser’s (2009) proposition that the hierarchy of evidence ought to be inverted to begin an exploratory study, with an analysis of expert opinion which included the consumer as a key expert and informant. The literature and policy review process allowed the context for the study to be conceptualised, informed further by the survey findings regarding Australian social work practitioners’ knowledge and experiences of EBP. The key methodological tools of policy analysis and in-depth interviewing garnered rich and informative data and thematic content analysis drew out the key themes and concepts from this data which fed into a recommended model of evidence-based practice and policy making. The accuracy, relevance, and workability of the model were reinforced through focus group testing. The presentation of findings back to participants and key stakeholders also related to the
ethical premise of the work to engage with service users and all other participants in an open, fair, accountable, and respectful manner which genuinely valued their contribution.

The methodology enabled an in-depth analysis of the bounded case studies of service users within mental health and homelessness sectors. By undertaking a systematic approach to data analysis which drew on the first-hand accounts from service users and service providers, assessed against the policy context for each case study, a picture began to emerge to inform the future direction of policy and service-delivery reform. The next chapter reports on the case study of service users involved with the homelessness sector in New South Wales. It uses the process of investigation and analysis described here to identify key themes and concepts and to establish the current state of play, as a means to begin conceiving ways forward for evidence-informed practice and policy making.
CHAPTER 5

Case Study: Homelessness

Homelessness is a complex social, economic, and political issue, which sees individuals and families in one of the most compromised and vulnerable positions within Australian society. It represents a manifestation of disparity of participation. A recurring theme for this study, in discussions with people who have experienced or are currently experiencing homelessness was the sense homeless people are treated as ‘non-persons’ and ‘non-citizens’. Hence policy and programming should facilitate more equality of homeless people given that homelessness means less than full membership of or participation in society. Given the marginal position of homeless people it is not surprising the service-user participation movement has been slow to progress within the policy-making process in Australia. The service-user perspective emphasised in this chapter offers an insight into the effects of such limited participation, the goals for those seeking to change the role of service users within the system of homelessness services and the ways in which EBP might either support or inhibit such aspirations. The case study first examines key bodies of literature that have influenced the adoption of EBP and participation specifically within Australian homelessness policy and service provision. It then sets the policy context for an analysis of EBP and participation in Australian homelessness services, outlining relevant components of federal, state and regional policy. Finally, and most importantly for this study, it reports on the findings from interviews with service users (n=11), focus groups with service users (n=3) and interviews with service providers (n=5) which explored homelessness service users’
experiences with and expectations of EBP and participation. In doing so the case study presented in this chapter:

1. demonstrates the gap between the actual experiences and perceptions of service users and the ideal-typical model of EBP, revealing service users’ values, knowledge, and experiences – as well as their communication networks - could be invaluable tools in evidence-based policy making where user participation is highly valued

2. examines the perceived failure of the human services sector to afford accountability and transparency regarding policy making and service provision to service users and ways in which service users are attempting to position themselves vis-a-vis existing power imbalances

3. explores the notion of expertise in today’s human service environment to position service-user expertise deriving from their lived experience of homelessness, and

4. examines the challenges for EBP in a human service environment where choice is limited by flawed modes of resource distribution. The limitations of choice during times of heightened crisis compromise the individualistic decision-making model of EBP described by commentators such as Gambrill (2006b) despite its avowed intent to take service users’ values, needs, interests, situations, and predicaments into account.

Homelessness emerged as a policy priority in 2008 within the Australian Rudd Labor Government (November 2007-June 2010). The rhetoric of social inclusion and evidence-based policy making suggested an increasing focus on building the evidence base to inform policy making and resource allocation in regard to homelessness. Within New South Wales, a version of evidence-based practice and policy making emerged
which looked to examples of good practice from the United States, United Kingdom, and Canada, with community sector organisations advocating for these models of practice as ‘evidence-based’. However, as the following case study demonstrates, EBP has failed to translate into significant process-oriented change or to impact upon the way in which service users experience the human services system.

The homelessness service sector comprised a broad and diverse array of government and non-government agencies, with varying processes and philosophies in the prevention and treatment of homelessness. Providers’ willingness to look to external models and sources of evidence to inform practice varied significantly across the sector as did community agencies’ responses to the federal government’s evidence-based approach. While many service providers relied on government funding, others were charities operating on donations and philanthropic funding sources with little direct accountability to government. This created a significant challenge to the streamlined approach to service delivery and policy making envisioned in the federal government’s policy blueprint *The Road Home*.

The homelessness service system was complex as were the issues faced by homeless people within the crisis environment in which the homelessness sector developed. Service coordination was extremely difficult given the myriad of services forming part of the homeless service network, including temporary and long-term accommodation services, Centrelink, public hospitals, general practitioners, mental health and outreach services, food vans and feeding programs, training and employment, counselling and therapy, drug and alcohol services, and legal support. Navigation of this service system was daunting and confusing for users, especially for those who had not mastered the informal information sharing, mutual support, and ad
hoc guidance services within the homelessness networks. Service users were at the mercy of agencies and enjoyed little choice in the matter.

The interviews conducted in this case study revealed policy makers at various levels of government recognised an increasing need for responsive preventative strategies to address homelessness and related issues but there was little indication of systematic, coordinated, evidence-based service provision on the ground. Services offered were determined, not necessarily by evidence or long-term strategic vision to end homelessness, but by organisational culture, capacity, and availability of resources. This, in turn, was determined by historical precedent, especially source of funding. To an outsider, decision-making processes were completely unknown or arbitrary and ad hoc, and lacking in transparency or accountability for service users.

**Literature overview: EBP, participation, and homelessness**

This literature review introduces the key bodies of work shaping attitudes and approaches to EBP and service-user participation within the Australian homelessness sector. It is not an analysis of the effectiveness, appropriateness or otherwise of specific strategies and interventions, but a summary intended to trace the influences on homelessness policy and programming.

Crane, Warnes, and Fu’s (2006) three nation study revealed an absence of rigorous evidence on the prevention of homelessness, particularly among older people, especially in the United Kingdom: “The arrangements for exchanging information and spreading good practice in housing welfare are disorganised, partly because housing welfare is not dominated by a single professional organisation” (Crane et al., 2006, p. 164). The diversity of organisations and agencies involved with homelessness prevention and intervention in Australia corresponded with this analysis, and strategies
such as Homelessness Interagency Networks and tools such as the Homelessness Information Clearinghouse marked attempts to overcome such disorganisation by sharing information and reaching consensus on elements of good practice.

As will be identified later in this chapter, discussions of EBP in regard to homelessness invariably drew on international studies regarding two models of housing support, housing first and common ground, rather than a process-oriented approach. The first influential study came from the United States (Padgett, Gulcur, & Tsemberis, 2006; Tsemberis, Gulcur, & Nakae, 2004). This longitudinal study randomly assigned participants – homeless people – to one of two models: the conventional continuum of care or the alternative housing first model. The continuum of care rewarded client compliance, especially sobriety, with permanent housing. It was similar to the transitional model used in Australia where clients ‘progressed’ through temporary crisis accommodation, to medium and eventually long term housing. The housing first model saw housing as a fundamental human right regardless of treatment progress (Padgett et al., 2006). It was a consumer-driven model recognising and respecting consumer choice. Its proponents have undertaken empirical quantitative and qualitative studies to measure the effectiveness and impact of the program against other intervention programs. It is an example of participatory EBP, whereby accountability was linked with empirical research and principles pertaining to parity of participation were fundamental.

In the United States, evidence of this nature led to the development of the common ground model, which was enthusiastically received by a number of government and non-government agencies in Australia, launching first in South Australia in 2006 and later in New South Wales in 2010 (Australian Common Ground Alliance, 2011; Common Ground Adelaide, No date; New South Wales Government, 2009a). The common ground model adhered to the housing first principle, offering
permanent housing solutions accompanied by a range of coordinated support services. The New South Wales Common Ground project was coordinated by non-government agencies, local government, and private sector construction companies with funding from state and federal government. United States Common Ground founder, Rosanne Haggerty (2007, 2008) advised the Tasmanian and South Australian governments on their homeless policies and programmes. An Australian Common Ground Alliance and accompanying advocacy movement developed on the premise of the housing first model’s proven effectiveness and status as a model that works, highlighting the way in which the Australian homelessness sector construed and used evidence.

The foyer model, which emerged mainly from France and the United Kingdom, primarily targeted young homeless people, and was discussed by the Australian Government (2008a) in The Road Home white paper. It was based on inconclusive evidence. It provided transitional housing for young people in urban services, with integrated support and mandatory participation in education, training, and employment-related activities. United Kingdom research demonstrated some success in housing outcomes but highly variable employment outcomes were achieved depending on the economic circumstances of the local community (Lovatt, Whitehead, & Levy-Vroelant, 2006). In the Australian Housing and Urban Research Institute (AHURI) (20009) synthesis of evidence used to inform New South Wales Government policy, there was little evidence regarding Australian implementation of the model despite foyer sites throughout the country. It highlighted the importance of location, client profile, and the range of services provided, implying the need for local research (Gronda & AHURI Research Synthesis Service, 2009). Nevertheless, in the absence of Australian effectiveness studies, the Australian Government (2008a) touted the foyer model as a promising response requiring additional resources. Throughout Australia projects were
established, including *This Way Home* in Newcastle, which had begun based on the common ground model, but been redesigned to resemble a foyer model of housing and service provision (Sylvia, service provider).

Case management has long been a component of homelessness services and features in many models and interventions. Gronda (2009) found effective case management paired access to affordable housing with persistent, reliable, long-term (more than six months), practical support. The YP\(^4\) project in Victoria attempted to measure the effectiveness of ‘joined-up’ case management services for homeless and jobless young people (Grace & Gill, 2008). Young people in the YP\(^4\) randomised trial were assigned to a control group in which they received services under the standard model, which was disjointed and could involve multiple contacts with different workers, or to the trial group in which they were assigned one case manager who provided long-term (two-year) support and acted as a single point of contact and coordination. Within the trial group, Grace and Gill (2008) found those participants who had over 20 contacts with their case managers, had significantly improved outcomes, particularly in the area of employment. These examples of research on case management models demonstrated there was evidence available to inform policy and practice in this area. The evidence regarding case management is interesting in light of sceptics’ concerns EBP could lead to rigid outcome-based management and guideline approaches to service delivery. In fact the findings endorsed flexibility, and supported calls from the professional field that case management required time, intensity and appropriate resourcing. Given the high value that service users placed on trust and respectful relationships with workers, as discussed below, it may be that this type of research could be a useful tool for service users and providers to advocate for models of long-term, intensive support.
The Australian Government (2008a) favoured an assertive outreach strategy, earmarking additional resources under the national homelessness plan, particularly targeting rough sleepers. AHURI’s initial analysis of the various assertive outreach models and existing literature, revealed the importance of framing assertive outreach within permanent housing solutions such as housing first and common ground, differentiating assertive outreach from other forms of outreach that offered crisis or temporary forms of comfort, support, and relief (Phillips, Parsell, Seage, & Memmott, 2011).

Chamberlain and Mackenzie’s (2008, 2009) Australian research in the Counting the Homeless reports based largely on Australian Bureau of Statistics census data, has been highly influential. Their cultural definition of primary, secondary, and tertiary homelessness became fundamental to the framing of homelessness within Australian policy (Australian Government, 2008a), although definitions and constructions of homelessness have been contested. Chamberlain and Johnson (2001) explored the tensions between literal, subjective and cultural definitions of homelessness, indicating that literal definitions were largely constructed on stereotypical (and often inaccurate) ideas of homelessness as rough sleeping, whereas subjective notions that depended largely on the individual’s perception of their own status as homeless or otherwise, were insufficient for measuring and researching the issue. The cultural definition of three-tiered homelessness was intended to describe homelessness in relative terms, against minimum standards for housing acceptable as the norm within the Australian context. It should be noted, however, that such a cultural definition may not have relevance to all Australian cultural groups, including indigenous cultures whose notions of home may vary significantly from European-influenced urban notions of home. Importantly, the notion of homelessness as a relative and cultural construct is in line with the notion that
participation can be assessed by exploring the accessibility of opportunities and resources considered standard within a specific societal context.

Chamberlain and Mackenzie (2009) highlighted the methodological challenges of accurate data capture on the homeless population, particularly through the census, as there was difficulty in locating and identifying the primary homeless and inaccurate identification of secondary homeless people living temporarily with friends and family. Consequently, they engaged service providers to increase awareness of the census among homeless people and used Supported Accommodation Assistance Program (SAAP) data to enrich census findings. The *Counting the Homeless* reports produced at national and state or territory levels provided a key source of information on trends in the homeless population and measures of effective interventions and prevention strategies for government and non-government agencies.

Beyond statistical monitoring and analysis of homeless populations, Chamberlain and Mackenzie (2006) have contributed to debates about the nature of homelessness and pathways in and out of homelessness. Through use of census data and case studies derived from interviews with SAAP clients, they developed three ideal types of homelessness intended to serve as heuristic devices for examining, not only how an individual or family became homeless, but how they overcame homelessness. The framework of the “youth career”, “housing crisis career”, and “family breakdown career” was a tool they claimed “sensitises us to the fact that different interventions are needed at different phases of the homeless career: prevention, early intervention and long-term support” (Chamberlain and Mackenzie, 2006, p. 199). This staged intervention model was adopted by the Australian Government (2008a).

Johnson, Gronda, and Coutts (2008) built on the career trajectory framework, indicating five ideal (problem) types precipitating homelessness: mental health,
domestic violence, housing crisis, substance use, and youth in problem households. Using qualitative service-user accounts, they examined ways in which service users on each pathway moved in and out of homelessness, highlighting the economic, familial, social, political, and health-related factors influencing homelessness. The pathways approach to homelessness supported Fraser’s (2006) notion of unequal participation as fundamentally a structural concern, not merely an individual crisis in identity. At the heart of each pathway or career crisis point was a poorly equipped system with punitive programs for deviants from the mainstream in an economy where housing was a profit-making tool in a highly competitive, over-priced market rather than a basic human right.

The structural failures regarding affordability of housing were examined by the National Housing Supply Council (2010) who indicated a growing gap between housing supply and housing demand. Even well-intentioned reforms in housing supply had failed to impact on housing affordability, because high demand meant high income earners were accessing housing otherwise suitable to low income earners. In adopting the heuristic device of the pathways approach, Johnson et al. (2008) challenged stereotypes and demonstrated homelessness was not merely a cause, but also an outcome of structurally induced social and economic problems: it was a cause, not merely an effect, of mental illness and drug dependency.

Hular and Kolar’s (2009) small qualitative research on citizenship and homelessness, based on interviews with 20 women who were sole parent families headed by mothers or grandmothers, who cared for of at least one child, in transitional accommodation in Victoria, found the degree of the women’s involvement in decision making with agencies varied greatly. While some felt in control of the decision-making process, others felt constrained by low levels of confidence and literacy. However, one participant noted her input to decision making increased as her confidence grew.
Participants felt more included in decision making with support workers, such as social workers and counsellors, but less included when dealing with public agencies, like government housing providers and Centrelink. Agency regulations precluded choice; you had to take what was offered because there was no other housing available. Participants expressed “a strong desire to re-establish a ‘normal life’ in which they were more independent and better able to be treated and recognised as an equal citizen rather than as a client who, by definition, is always in an unequal position of power and influence” (Hular & Kolar, 2009, p. 42).

The Australian Government used the language of social inclusion or exclusion to frame homelessness. The Australian journal *Parity* is published ten times annually by the Council to Homelessness. Focussing on homelessness and social inclusion, the editorial of the May 2010 edition stated:

Social inclusion has been eagerly embraced by social justice and anti-poverty advocates in Australia, including the homelessness sector. As a term it sums up, quite brilliantly what we are all striving for – an end to exclusion, but also the recognition that things like homelessness are multi-dimensional, both in cause and effect (Burrell, 2010, p. 4).

The federal Labor Government’s policy focus on homelessness and release of additional resources under the social inclusion agenda were predictably welcomed by the community services sector. However, this rebranding exercise did little to change non-government homelessness services on the ground. Despite the rhetoric of consumer choice and service-user participation, there has been limited direct participation of homeless people in decision making and policy making, compared to sectors like mental health and disability, even though homeless people as active decision makers were part
of the Australian Government’s social inclusion agenda informed by the vision all Australians should: “Have a voice so that they can influence decisions that affect them” (Australian Government, 2009c; Home; ‘The social inclusion agenda’ section). Parity committed its August 2009 edition to the notion of ‘homeless voices’ in which practitioners, policy makers, and academics considered homeless people’s participation in decision making. Service-user perspectives emphasised “having a voice is about having the opportunity to talk about your life” (Claire, 2009, p. 17). Involvement of homeless people in delivery of human services was essential because professionals were seen to lack important insight and information which only those with experience of the situation could offer. Furthermore, such participation was a human right (Adrian and Kerrie, 2009).

There was a dearth of literature pertaining to the specific involvement of homelessness service users in activities such as conducting research or systematic reviewing. One study from Canada indicated that the inclusion of formerly homeless people on the research project’s advisory committee was useful, as, alongside service providers and government agency representatives, they were able to constructively advise regarding issues of participant recruitment, methodology and data interpretation and highlighted the importance of qualitative devices to add depth to quantitative methods (Tolomiczenko & Goering, 2000).

As outlined in the literature review (Chapter 3), participation is a thorny notion and the kind of participation envisaged within neoliberal welfare programs differs vastly from that arising from the service-user literature which is built on a foundation of rights-based citizenship. As shown within this and the mental health case study which follows, participation usually connotes participation of those already in the service system. This is problematic within the homelessness sector where the people with the
lived experience of long-term homelessness are ‘hard to reach’. Often they have been deliberately excluded from the very service sector now seeking to address their problem through their failure to participate (through employment) or cooperate (with the rules of accommodation services). These are excluded and marginalised people at the hard end of homelessness who therefore present a problem whatever construct is used, whether service-user choice within neoliberal rhetoric or parity of participation from welfarist and feminist discourse. It is against this backdrop EBP and participation in federal and New South Wales homelessness policy needs to be viewed.

**EBP and participation in federal and New South Wales homelessness policy**

Key policy documents at federal, state, and regional levels were analysed to identify the ways in which governments were engaging with the concepts of EBP and participation and the extent to which these concepts influenced policy making. The primary documents analysed for this purpose were:


The policy analysis provided a context in which to consider the responses of service users and providers to questions related to evidence and parity of participation in the homelessness human services sector.
National – federal – policy agenda

The national policy agenda on homelessness was reflected in two key federal Government documents produced during the Rudd period. The May 2008 green paper Which Way Home: A New Approach to Homelessness was a consultation paper to instigate and stimulate national discussion on homelessness reform strategies (Australian Government, 2008c). This document and the corresponding consultation processes fed into the white paper released in August 2008 called The Road Home: A National Approach to Reducing Homelessness. The Road Home set two ambitious, overarching goals: (i) halve overall homelessness by 2020 and (ii) offer accommodation to all rough sleepers by 2020 (Australian Government, 2008a). The green paper Which Way Home presented homelessness as a priority in the government’s “social inclusion agenda” (Australian Government, 2008c, p. 9) with its aim the “economic and social participation” of all citizens (Australian Government, 2008c, p. 70). Participation referred to involvement in mainstream life and work in Australia. Participation was seen as the end goal of policy, not necessarily as part of the policy-making process. In terms of Fraser’s (2000, 2008a) parity of participation framework, it emphasised maldistribution as contributing to homelessness. Homelessness was seen to have risen despite, or perhaps in response to, an overall increase in prosperity in Australia.

The green paper criticised the system of homelessness services, which operated in crisis mode, and failed to prevent and respond to long-term needs associated with homelessness. It was critical of SAAP, the main recipient of federal government funds to address homelessness and central to the provision of emergency or crisis accommodation. Despite discussions of homelessness as a complex social, cultural, economic, and health problem, the national policy documents defined homelessness in terms of three levels of physical housing provision as follows:
1. **Primary**: Sleeping rough

2. **Secondary**: Temporary accommodation provided by a service or through friends or family

3. **Tertiary**: Boarding houses, caravan parks, or other temporary accommodation with no secure lease and without private facilities (Australian Government, 2008c, p. 18).

In this study service provider Christine was perplexed that “we were talking about homelessness and saying that homelessness is not just about houses, it's about connections, it's about social inclusion etc. We're saying all this but our definition of homelessness in Australia is purely about the type of housing you're in”.

At the same time, the Rudd Government strongly emphasised the need to build the evidence base on homelessness, viewing improved research – which included data collection – as fundamental to its policy strategies. Existing data sources – the Australian Bureau of Statistics and SAAP reporting – were significantly flawed. Australian Bureau of Statistics data provided only a snapshot of census night and, in this study, service providers especially criticised the methodology used (Christine and Pam, service providers). SAAP client data was significantly shaped by the composition of the services received, rather than reflecting actual demand or need. Hence a key strategy included funding for research to build the evidence base on homelessness and what to do about it:

There is an urgent need to improve the evidence base to inform the delivery of high-quality services to people vulnerable to homelessness. Since the pool of money is limited, it is important that funded programs are cost-effective and work to protect and enhance the life chances of people who are homeless or at
risk of homelessness. People who are homeless, or are at risk of homelessness are among the most vulnerable in our community – it is vital that interventions actually work and that they do no further harm (Australian Government, 2008a, p.58).

In August 2009, the Rudd Government announced the allocation of $11.4 million over the subsequent four years to support research in this area (Plibersek MP, 2009). The government released a national research agenda aiming to:

1. Improve data and measurement of homelessness
2. Inform and improve the service system and practice, including evaluation
3. Increase understanding of homelessness (Department of Families, Housing, Community Services and Indigenous Affairs, 2009b, p. 4).

$4.1 million supported research partnerships with the University of Queensland, Swinburne University of Technology and Flinders University of South Australia and $1.5 million was distributed amongst 16 universities, institutes and community agencies to deliver targeted research projects (Department of Families, Housing, Community Services and Indigenous Affairs, 2010).

At the time, the premier group conducting research in this area was the Australian Housing and Urban Research Institute (AHURI), a national, not-for-profit institute funding, conducting, and disseminating research on housing, homelessness, and cities to inform the policies and practices of governments, industry, and the community sector, and stimulate debate in the broader Australian community (Australian Housing and Urban Research Institute, 2011). The federal government significantly increased its level of funding support to AHURI in 2009 (Plibersek MP, 2009) and the federal and
New South Wales governments commissioned AHURI to produce reports and research publications to inform their homelessness policies and strategic priorities.

In 2008, Australian Minister for Housing, Tanya Plibersek launched the National Homelessness Information Clearinghouse, a website to facilitate the sharing of information about homelessness and good practice in the service sector (Plibersek MP, 2008). The website disseminated information, including research for practice and policy making. The clearinghouse was a potential knowledge management tool within the evolving EBP system to indicate the way in which government could support and manage evidence to support organisational and practitioner level decision making. It was a move to show the government’s seriousness about, and commitment to, evidence-based policy making in the area of homelessness. However, it was difficult to determine the extent to which the research emerging from government-funded research initiatives indeed influenced policy.

The Australian Government (2008a) in The Road Home white paper referred to various models, including foyer, common ground, and assertive outreach as examples of practices it would support due to their international success:

For rough sleepers, assertive outreach models have been successfully trialled in the United Kingdom and the United States of America. These models involve working intensively with people sleeping rough, connecting them to sustainable long-term housing and health services (p. 47).

The Australian Government considered cost-benefit analysis an important component of the research to build the evidence-based regarding homelessness and, in general, had emphasised cost effectiveness as a component for measuring value of its interventions (Banks, 2009). International studies had shown the exorbitant cost of
medical and legal services, crisis and temporary accommodation, and food and basic welfare in comparison to the cost of long-term, permanent housing solutions (Berry, Chamberlain, Dalton, Horn, & Berman, 2003). AHURI’s research indicated additional health, justice, and social welfare related costs of homelessness could be reduced if mainstream services could meet the needs of homeless people. This far outweighed the cost to government of specialist homeless programs such as SAAP and the Transitional Accommodation and Support Service (Flatau, Zaretzky, Brady, Haigh, & Martin, 2008). However, this was quite a different approach to evidence-based practice and policy making than that discussed in the academic literature. The EBP movement has had a focus on what works, but not necessarily on what it costs. In this instance the relationship between new public management and its emphasis on economic rationalisation was seen to shape the interpretation of EBP by the federal government.

**New South Wales policy agenda**

**New South Wales Homelessness Action Plan**

Like the federal government, the New South Wales government stressed the importance of evidence-based policy making and practice calling for research evidence to inform their homelessness responses (New South Wales Government, 2009c). Its first step was the development of the *New South Wales Homelessness Action Plan*. The New South Wales government commissioned AHURI to synthesise contemporary national and international research in the report *Evidence to Inform NSW Homelessness Action Priorities 2009-10*, to inform the development of its statewide action plan (Gronda & AHURI Research Synthesis Service, 2009; New South Wales Government, 2009c).

The action plan described evidence-based decision making as an ongoing process and noted the importance of (i) cost-effectiveness measures and improved data
collection and management regarding service usage and (ii) collaborative research programs and evaluation strategies. The linking of evidence-based decision making to “performance indicators” (New South Wales Government, 2009c, p. 21) is a strategy of new public management rather than EBP. Hence the action plan confused information-based decision making with evidence-based processes (Gray et al., 2009). Meshing the findings of rigorous empirical research with politically charged program evaluation and performance measurement was problematic given the bias arising from the contingent government-service provider relationship. Service providers were unlikely to jeopardise their continued funding and had a vested interest in demonstrating service effectiveness (Pawson, 2006, Weiss, Murphy-Graham, Petrosino & Gandhi, 2008).

The New South Wales Homelessness Action Plan set the overarching targets of a reduction of 7% in the overall level of homelessness, 25% in the number of people sleeping rough, and 33.3% in the number of homeless Aboriginal people in New South Wales by 2013 (New South Wales Government, 2010, p. 13). The plan was framed by seven principles, two of which were particularly relevant to this study. Principle four stated the New South Wales government’s response to homelessness “will respect and protect the social, economic and civic rights of people who are homeless or at risk of homelessness” and “recognise and value the right of the individual to participate in decision-making processes about their own future” (New South Wales Government, 2009c, p. i). Principle seven claimed: “Our response to homelessness must be guided and informed by evidence” (New South Wales Government, 2009c, p. i).

The action plan described homelessness not only as the absence of housing, but also a “lack of connectedness with community” (New South Wales Government, 2009c, p. 5). It cited social and economic participation – employment and housing – as goals of service interventions for people at risk of, or experiencing, homelessness. In 2010, the
New South Wales government initiated two key activities to ensure widespread representation: (i) the Premier’s Council on Homelessness and (ii) Consumer Advisory Council.

Following a state election in 2011 the Labor government which had devised the *New South Wales Homelessness Action Plan* was replaced by a Liberal government and it was, as yet, uncertain to what extent the existing policies would be retained. During focus groups for this study, held after the election of the Liberal government, there was significant scepticism expressed about the level of commitment by the new government to resolving the issue of homelessness and working in partnership with people with experience of homelessness, and the inactivity of the Premier’s Council on Homelessness was noted. However, indicators such as the direction to Housing NSW (the New South Wales agency responsible for social housing and homelessness services) to participate in a working group with representatives of the Consumer Advisory Council, suggest some recognition by the new state government to continuing the momentum towards participatory mechanisms (Public Interest Advocacy Centre, 2011).

**Premier’s Council on Homelessness**

The Premier’s Council on Homelessness was a ten person council which offered high-level advice to the New South Wales government to guide the development and implementation of its action plan. Its membership comprised mainly academics and professionals with practice and research knowledge of homelessness.

Of 77 action points in the *New South Wales Homelessness Action Plan* one concerned service-user participation. It stated, in order to promote partnerships across levels of government, business, consumers and the not-for-profit sector the government
would include “homeless people’s views and advice in future policy and/or program planning” (New South Wales Government, 2010, p. 35). Subsequently, in 2010, two positions on the Premier’s Council on Homelessness were filled by people who had experienced homelessness, one person with over 20 years and another with three years’ experience of homelessness. Appointment to the service-user positions on the council resulted from an application and selection process, although it was unclear as to the criteria used in deciding appointments. There was also a tendency towards Sydney-based representatives on the council, which may have been reflective of the high concentration of homelessness in Sydney, Sydney’s position as an administrative centre for many services and agencies, or a bias towards city-based expertise and experiences.

In regard to implementing and monitoring the NSW Homelessness Action Plan, Premier Kristina Keneally stated in a media release entitled Expert group to advise Premier on homelessness, “I want advice from the people who deal with this issue on a daily basis and have firsthand experience, including people who have slept rough” (New South Wales Government, 2010, p. 1). The wording of this media release positioned the council members as possessing “expert knowledge”, indicating the shift towards conceptualising service-user knowledge as expertise which could make an important contribution to policy making.

*Consumer Advisory Council*

Originally advertised during a tender process as a series of community forums throughout New South Wales for people who had experienced homelessness to provide input into policy and programming, this second activity became a government-funded initiative driven by the Public Interest Advocacy Centre and its Homeless Persons’ Legal Service. Recognising the limitations of the original proposal in reaching the most
vulnerable, gleaning meaningful input, and risking criticism of tokenistic participation, the Public Interest Advocacy Centre coordinated the consultation process through the Consumer Advisory Council (Homeless Persons' Legal Service, 2010). The Consumer Advisory Council conducted a survey of homeless people in Sydney, Newcastle, and the Nepean and facilitated forums to provide input to the Premier’s Council on Homelessness regarding key issues and concerns of people with first-hand experience of homelessness. The most recent development of the Consumer Advisory Council was the establishment of a working group bringing together Housing NSW representatives and service-user representatives to make policy recommendations based on the findings from activities such as surveys and forums (Public Interest Advocacy Centre, 2011).

Both of these groups were representative and advisory. The government retained power and there was little evidence of service users exerting any real influence over high-level decisions or policy. Thus despite the rhetoric to increase the community connectedness of marginalised people, there was little in the action plan to suggest how this would be done and, at best, these were tokenistic strategies to enhance participation (Cruikshank, 1999).

**Local and regional policy agenda**

As part of the rollout of the New South Wales Homelessness Action Plan, regional committees were charged with developing localised strategies to implement the New South Wales government’s priorities, and two of these have been selected as examples of the way in which the policy translates into action at a regional level. The *Hunter* and *Central Sydney Regional Homelessness Action Plans* translated the federal and state policy objectives into local action strategies (Housing NSW, 2010a, 2010b). Both drew heavily from the AHURI research synthesis commissioned by New South Wales
Government as a source of evidence to guide their actions (Gronda & AHURI Research Synthesis Service, 2009). Key government and non-government providers were invited to a workshop to develop the Hunter and Central Sydney action plans or to provide written submissions. The action plans consequently reflected the interest of participating service providers with actions largely program based, either extending existing programs or introducing new ones.

The Central Sydney plan did not explicitly prioritise the involvement of service users, while the Hunter’s plan highlighted the lack of service coordination and mechanisms for service-user participation. Both plans, however, identified improved data collection and connection between data analysis and service provision as priorities. Statistical data about the composition of homeless populations, and service usage and demand data were considered important. The City of Sydney, as a local government body, had been undertaking biannual ‘street counts’ to identify the numbers of people sleeping rough or in hostel or overnight accommodation to provide a more accurate picture of the severity of the issue and impact of interventions (City of Sydney, 2010). However, the Central Sydney plan acknowledged their valuable data only reflected one Local Government Area (LGA) and more consistent processes across the region were required. There was no indication of the ways in which research might inform local service planning and program implementation.

Examination of the translation of policy from federal, to state, to local levels revealed how service-user participation and EBP could be relegated to rhetoric when overlooked in action plans and local strategies. There was little demonstration of a critical or rigorous understanding of evidence and at state and regional level there was indication of over-reliance on the one research synthesis produced by AHURI. There was no indication that a process-oriented approach to EBP would be adopted or that
evidence would perform any function other than as a one-off source to guide initial planning and policy decisions. Essentially, what started out in federal policy as a grand and idealistic approach towards participation and EBP that was framed within a social inclusion and accountability agenda, became diluted by the inability to articulate how the principles, strategies and processes could actually be implemented at state and regional service levels.

**Overview of participation mechanisms**

Unlike the disability and mental health sectors, the inclusion of people with experience of homelessness in decision making had only recently begun to emerge in Australia. Formal and structured consumer advisory groups were a relatively new development in this sector and had been guided by a human rights perspective, with public interest advocacy and legal services taking a lead in establishing and supporting such groups. In Victoria the Public Interest Law Clearing House (PILCH) supported the establishment of a homeless persons’ consumer advisory group in 2006, and since that time an eight person group had provided consultation and advice to legal, government and community agencies, facilitated consumer forums, spoken publicly on the issue of homelessness and written about their experiences and ideas regarding homelessness in regular newsletters (Public Interest Law Clearing House, 2008). A similar model had also been developed in Queensland. In New South Wales in 2008, the Public Interest Advocacy Centre (PIAC), through their Homeless Persons’ Legal Service supported the establishment of Street Care, with pilot funding from the City of Sydney. Street Care comprised seven people with experience of homelessness and advised government and community agencies regarding strategies to effectively consult with and engage homeless people in their activities and decision-making processes (Public Interest
Advocacy Centre, 2009, 2010). While seemingly similar to other models of consumer advisory groups, there were a couple of interesting distinctions about Street Care, which indicated recognition of the challenges for representativeness in this type of participation model. The first was that its intention was to act as a source of advice regarding the participation of homeless people in decision making and as a conduit to establish participation mechanisms, not as the actual primary source of consultancy. This approach recognised that the group of seven, self-appointed and specifically targeted individuals could not possibly represent the diversity of all homeless and hard-to-reach people, but they could provide insight, knowledge and ideas for how this might be done better. The second was that it recognised the tendency toward urban and Sydney-focused participation. In forums and while the original group was Sydney based, the concept of Street Care had been expanded into regional centres. For example, in the Newcastle and Hunter region the Newcastle and Hunter Homelessness Interagency Network (2011) had agreed to support the establishment of a local Street Care group. These groups, supported predominantly through legal agencies, were instigating formal participation activities in the homelessness sector, and had been influential and involved in government-funded initiatives such as Consumer Advisory Councils.

**Service-user perspectives on participation**

The service-user participants in this study had participated in various formal and informal advocacy and advisory activities in urban and regional New South Wales and Victoria. Given the limited formal mechanisms for service user participation in the homelessness sector and their immaturity, the interviewees for the case study (n=11) and focus group participants (n=3) viewed themselves as pioneers in the service-user participation movement. All participants had taken part in some type of formal advisory
or representative role as homelessness service users, including providing advice to
government and community agencies in relation to their experience of homelessness,
speaking publicly about homelessness at forums, functions and conferences, writing
about homelessness in newsletters and sector-related publications and conducting
surveys and other information gathering strategies with homeless people. Most also
noted that a significant part of their advocacy work was conducted in informal and
personal ways through sharing information and advice with peers and advocating to
agencies on the behalf of their peers when they felt services were substandard or their
needs were not being met. A number had been advocating and speaking publicly about
the issue of homelessness for years prior to the establishment of any formal advisory
groups.

**Disparity in participation**

During the interviews service users described ways in which they were prevented from
full and fair participation in society and in human service provision. They perceived
homelessness as a consequence and cause of inequality: “Different reasons brought us
into homelessness. Homelessness then created different problems” (Jane, service user).
Service users and providers agreed people experiencing homelessness were poorly
represented in service development and delivery. In a broad sense, they described
homelessness as the ultimate realisation of a disparity of participation. They talked
about the status of being a “homeless person” in terms of “non-membership” in society
or non-citizenship since they lacked the same rights or privileges as mainstream
citizens, such as access to safe and secure housing and control over where they lived.
Melanie (service user) described her drug use, criminal behaviour, and mental illness
manifesting in her “inability to live within society as a [full] citizen…” Other interviewees too, experienced rejection by mainstream society and felt they didn’t fit in:

I went for a walk the other day and there was a woman and she looked like she hadn't had a shower in about twelve months, because they hide in the bushes. They hide from society from where it's got them. And society really done its danger to me… (Sue, service user).

They felt excluded, unwelcome, and different from the rest of society. Laura (service user) described her experience as a victim of violent assault while homeless. The police suggested it would be difficult to investigate the matter because she had no fixed address. Jane talked about her poor health from years of living on the streets and told stories of friends who had died with no caregivers to support them, or to respond to health and suicide-related emergencies arising from severe housing and financial stress.

Social inequalities led to serious, chronic, and even critical limitations to the person’s ability to participate in mainstream society and access health and legal services. Such inequalities were due not only to homelessness, but also to myriad complex and serious consequences of social isolation. Fraser’s (2001, 2008a) theory of parity of participation offers a means to resolve social injustices if policy makers and practitioners were to consider whether a proposed policy or intervention would create further disparities, intentional or otherwise. Service users highlighted ways in which they were further marginalised by the very services purporting to help them and suggested strategies and relationships which were important in overcoming subordination and striving towards full social participation. Service provider Tim suggested:
… people with the highest needs, so the people with drug and alcohol problems or … people with like serious mental health conditions are excluded from the services because they want this idea of the perfect homeless person who's well behaved and well-mannered and doesn't kind of arc up and get angry. But people in that situation are going to be angry, like how could you not be and it's just this stupid situation where essentially services aren't being tailored to the people who need them.

The experience of homelessness was described as being frustrating, lonely, frightening, overwhelming and confusing. Service users and service providers described a human service system that was complex and difficult to navigate, certainly for people expressing elevated levels of stress and anxiety and often even for professional workers in the industry This chapter focuses on the structure of the service system and inbuilt barriers to service-user participation and then explores how service users obtained and used information, particularly via word of mouth, to navigate this system. Many participants did not meet the eligibility criteria for services: a single person was rejected because families were given priority; a young person was denied services reserved for adults despite living independently; a person in tenuous and insecure housing was turned away; and so on. Those most difficult to place were categorised as ‘difficult clients’. Male respondents noted the informal, though highly effective system of blacklisting, whereby service providers, particularly in emergency and medium-term accommodation services, warned one another about problematic ‘difficult clients’. An aggressive outburst at one accommodation service could have dire consequences. Six service-user participants (Sue, Isabelle, Rodney, Paul, Jane, and Steve) described the risks associated with complaints about service delivery and the ensuing difficulties in
obtaining further services. Rodney recalled his difficulty in managing his frustration with a service provider and the consequences:

You couldn't, shouldn't get your point across without being angry and somebody takes that idea wrong and says, ‘Sorry, not dealing with you, shop closed, go away’. And you walk away and you go ‘Gee, now I've got nowhere to live and I've just upset the housing people and what do I do now?’

The type of subordination described by Fraser (2001, 2008a) was apparent in the way that the service users experienced power in the decision making processes around their homelessness and the related service provision. Weakened by severe crisis and unable to take control of her situation, Jane (service user) explained her frustration with:

… the system set up and entrusted with the care and protection and people within its society and it’s clearly failed in that. And people are angry, people get discriminated against. Not just from society as a whole, but from the very services that are there to, set up to, help protect them and help them on their way and help them exit the cycle of homelessness a lot quicker.

Some service users described positive experiences in which they were able to achieve the outcomes important to them. The key factor was the quality of the relationship with the worker, his or her ability to listen, show care, and advocate for client interests. Feeling respected, listened to, and cared for were transformative for service users. When asked about the qualities of a good service, Jasmine (service user) stated:

I think it’s caring … because any worker can be a worker if they study for a year. But they need to have compassion, they need to be, they need to empathise, yes, with people, and they need to care for them.
Ultimately, however, the workers in the human services system and their managers were seen to have immense power, inherent in the daunting service system and arbitrary decision making of workers, which could be used for good or ill. Greg (service user) described a positive experience with community housing service providers, due to his case manager’s ability to advocate on his behalf:

Whoever's got the biggest voice gets the most for their clients. I've no doubt about that. And fortunately my case manager had a big voice and she wasn't going to let me slip down the chain so to speak.

At an individual level it was seen that the impeded participation of people with experience of homelessness was often exacerbated by a daunting service system and a perception of arbitrary decision making that was largely in the hands of the workers. A person with significant experience and knowledge of the system (a veteran), with a worker willing and able to advocate on their behalf or experiencing stability and security, was able to overcome some of the barriers to participation at an individual level.

The interview respondents, service users and service providers, iterated that participation of service users at a representative level lagged behind service-user participation movements in areas such as disability and mental health. Respondents reported low and unsatisfactory levels of service-user participation in policy making resulting from the perception homeless people were incapable of participating in high-level decision making due to their high needs and personal crises or because they lacked the skills and knowledge required for participation. As a result, service providers tended to speak on behalf of homeless people. This was exemplified by the notable absence of service-user representatives on the Prime Minister’s Council on Homelessness, which
comprised people who were considered to be experts from various agencies and institutions (Australian Government, 2010). Nevertheless, the respondents in this study saw enormous potential for homeless people’s participation despite complex personal needs, illiteracy, limited access to technology, and poverty. Such challenges for participation were seen as factors to be considered in designing inclusive and flexible participation strategies. Service provider Pam wondered whether the crisis nature of homelessness services could be a contributing factor to low consumer participation, suggesting disability and mental health services had their roots in family advocacy and lobbying movements where the consumer voice had been intrinsic to their establishment. However, homelessness services were established as an emergency response to the housing crisis and growing number of homeless people. Service provider Christine suggested there was significant stigma associated with homelessness because, unlike mental illness or disability, and like substance abuse, it is seen to be the fault of the homeless individual.

**Motivations to participate**

The interviewees in this case study were all involved in some type of participation or consumer-representation activity. As such, it was expected they would place high importance on participation and might not necessarily represent the broader homeless community. Nevertheless, the descriptions of their aspirations and motivations were enlightening in regard to the roles service users see for themselves in practice and policy making. Almost all described their participation as an opportunity to increase people’s understanding of, and empathy towards, homelessness: “Having a voice” or “giving a voice” (service users Melanie, Jasmine, Penny, Jane, Greg and Steve) expressed the right of homeless people to speak for themselves. Most interviewees said their
experience of homelessness had given them unique insight and a sense of obligation to help others who were at risk of, or experiencing, homelessness. Melanie, Paul, Penny, and Jane believed their confidence, communication skills, and opportunism had made it easier for them to represent other homeless people. They saw it as their duty to advocate for and speak on behalf of homeless people. Paul aimed to:

… try and empower and encourage the guys to come forward and act in their own interest. So many of the homeless think that they're not members of society. We are. And we've got to stand up and be counted. We've got to interact and work with services to make services better. And the past and traditionally it's always been 'we know what's best for the homeless people’. Well that's not always the case.

It was seen as a privileged position to be advocating for or representing the interests of homeless people. Service users Sue, Steve, Penny, Paul, Jane, Isabelle, and Greg described their aspiration for their advocacy work to generate service improvements and shed light on the failings of the system. Sue also described the potential for her work as a consumer representative to be a career stepping stone to help her move into a mentoring or caseworker role, whether voluntary or paid, while Rodney (service user) reflected on his increased self-esteem and sense of self-worth gained from participating in advocacy and representation activities.

Consultation and engagement with service users in service development and delivery was seen as an ethical imperative. All service providers believed their work and that of others in their sector could be improved through service-user participation. They saw that directly seeking service users’ feedback and ideas was crucial to devising appropriate policy and programs. Some had sought this feedback through formal
mechanisms, such as advisory groups and used processes such as meetings, surveys and forums to gain feedback, as well as facilitating service user input to legal and policy consultations. John described how “what really drove that was the stories of consumers and their experiences, trying to get into and maintain tenancy of public housing. They also provided evidence for the parliamentary committee last week and almost had the committee in tears as they were talking about … their experience of homelessness and public housing. So their ability to influence decision makers in government is huge”. Other service providers sought service user input on a more ad hoc basis, engaging with people who used their services on an as needs basis, and most noted that they saw a need to improve the way their agencies and organisations sought the participation of service users, because they believed there was a need to understand the perspective of service users in order to do their jobs better.

Despite the reservations and limitations expressed below, there was a unanimous belief expressed by respondents that service users ought to have opportunities to contribute to decision making at all levels regarding the services that affected them and that the right to representative types of participation was important.

**Limitations of participation mechanisms**

While the motivations for participating in representative activities were clearly articulated by study respondents, there were a number of reservations and concerns expressed about the ways in which participation activities were structured and implemented.

There were some reservations about representative participation expressed by Paul who noted that some people became involved in advocacy and activism work because “they have these personal axes to grind. That scares me. Because all the good
work we have done can be all unravelled …”. This concern reflects the tenuous and fraught nature of participation in which the service users actually have limited power that can be retracted at any time. Having a personal agenda was seen as contradictory to the principles of representative participation, which was, as perceived by the service users in this study, a process to support improved opportunities for the general population of people with experience of homelessness.

Service users noted a number of challenges for themselves and their peers in acting as representatives and identifying as homelessness service users. Paul and Penny noted that the personal circumstances and challenges associated with the experience of homelessness often made participation challenging. Service users were not always comfortable retelling their personal story of homelessness and were wary of being patronised and pitied. For some, such as those fleeing domestic violence, it was not considered safe to identify publicly in representative or consultative forums. Further, it was noted that service users had a myriad of personal circumstances that constantly emerged and re-emerged which would take priority over participation activities, such as housing instability, health issues and financial problems, and service users in this study noted the challenges for group participation activities where the capacity for their peers to commit fluctuated dramatically. Service user Jasmine noted that her peers had become resigned to their circumstances living in temporary and medium-term accommodation facilities and that speaking out publicly about the issues affecting them wasn’t a consideration because “they just go with it and they think this is the way life's going to be for the rest of their lives”. While these concerns primarily relate to challenges associated with the identity and experience of homelessness, there were a number of limitations to effective participation that related to the structure of the actual participation mechanisms.
In the emerging participation movement in the homelessness sector there were, as yet, relatively few mechanisms for formal participation and relatively few (when compared with mental health sector) service users actively taking part in advocacy and activist activities. Service providers indicated that there was often a very small group of service users who were constantly called upon to contribute their time and expertise to committees and consultation processes and to act as representatives or spokespeople for the wider population of homelessness service users. Two concerns emerged from this limited pool of representatives. First, that those individuals were exploited, over-relied upon, and prone to burn out, because service providers and policy makers were attempting to fulfil a perceived obligation for service-user input, without being willing to attract and engage with a diverse, new group of homelessness service users. The criticism was that it was unfair to rely too heavily on one or two individuals and that this was often done without due consideration to the welfare of the participating individuals. Secondly, the concern expressed by service providers was that the participatory mechanisms that enabled over-reliance on one or two individuals led to service-user input that was not necessarily representative of the wider service-user population. It should be noted that these concerns were more emphasised by service providers than by the service users, who seemed highly motivated to participate and, in light of the limited opportunities to participate, were desperate to take opportunities that arose to contribute their ideas and input.

Three service providers expressed that their ability to facilitate and enable participation of service users in decision-making processes was limited by the lack of resources available to fund such activities. They had limited capacity to pay service users for their contributions to activities such as service planning, surveying and consultation and limited staffing resources to support such activities. It was noted that it
was difficult to obtain funding to support such activities. While three service providers
described ways in which consultation with service users had been incorporated into
everyday work practices, such as informal discussions on proposals and policies with
known service users, they felt that effective participation and representation of service
users required some degree of formal structure and therefore required funding to enable
such a structure to be implemented.

Service users noted that some activities, where the supporting agency had access
to funds, resulted in payment, usually in the form of a voucher or reimbursement of
costs incurred such as travel and food, but that many other activities were unpaid. There
were challenges for providing cash payment which might require the service user to
report additional income to Centrelink and jeopardise their receipt of the social security
allowance. Lack of payment for services rendered by Isabelle as a service-user
representative was problematic because each time she took part in an activity she
incurred costs associated with care for her child and travel, but when she questioned
whether she would be adequately paid for her contributions she claimed “It was like ‘Oh
you're being money hungry or something’. And it's like well, you know, I live below the
poverty line, so I want to contribute but, you know … I'm being expected to give so
much of my time without, you know any sort of … compensation”. Steve and Mike saw
that because their expert knowledge of the system of human services and of
homelessness had been gleaned over numerous years of lived experience, it was a
valuable commodity that was worth financial compensation. Steve was very interested
in providing training and consultation services to improve service providers’
understandings of the experience of homelessness, but he jokingly noted: “I'm not doing
it for nothing, I know what it's worth!”

In general, the participation mechanisms which service users and service
providers described saw that authority for decision making was retained with service providers and government agencies, with service users offering input and ideas which may or may not have been taken up by authoritative decision-making bodies. Those service users willing and able to participate as representatives were required to function within forums and mechanisms dictated by the service providers and policy makers. Service user Laura noted that illiteracy was one major deterrent to participation and that she’d only been able to take part in consultation and surveying activities where she’d had literacy support from peers or agency staff. Service provider Pam was cynical of the way in which many of her fellow service providers expected service users to be open and articulate in providing their feedback and ideas within workplace environments which were unfamiliar and uncomfortable for most service users. She saw that service providers expected the service users to come to them if they wanted to participate, suggesting that:

… you want to consult with them then you need to consult with them in the way that they choose to be consulted with. So, it's come out of your offices, put on your walking shoes and go for a walk. They will talk, people will talk more openly in an environment that they're comfortable with, that they feel that they have some control over, you know, into their space by their grace.

Service user Isabelle, who’d taken part in a number of different committees and forums, felt that agencies tended to recruit service-user representatives who would be compliant and who’d had positive experiences in the service on which they were consulting. She suggested that many people with experience of homelessness were not aware of the opportunities to participate which existed, because they were not invited to participate. The power over who participated was largely retained by the agencies
themselves and so a true representation of service-user ideas and input was not possible.

So, while respondents in this study retained a strong belief in the principle of service-user participation, there were concerns about manifestations of so-called participation that failed to challenge existing decision-making power structures and complexities for participation that required a sensitive and flexible approach.

**Service-user expertise**

Much of the value placed on service-user participation related to the perceived quality of service-user knowledge and the unique perspective of the lived experience of homelessness. Interviewees described the expertise derived from experiencing and understanding the complexities of homelessness and the failings of the human services system. Service user Paul stated:

> The homeless people themselves are the experts. And unless we are a part of, you know. And I know a lot of people will say, ‘But you're part of the problem, how can you be part of the solution?’ Well no-one understands the problems better than a homeless person.

Service users Paul, Jasmine, Penny, Jane, Greg, and Rodney made clear distinctions between the type of knowledge gleaned from academic study (the EBP approach) and lived experience (service-user participation model). A “textbook” approach could not provide the level of understanding required to address issues surrounding homelessness. Service user Jasmine argued, “We're not just reading from a textbook or reading papers or anything. So, like, the guys know what goes wrong and what goes right”. However, academic knowledge was not disregarded entirely but it was seen as crucial for researchers, policy makers, and practitioners to work closely with service users and to
incorporate personal knowledge with their practice and policy-making decisions (collaborative research approach). These types of expertise were seen as complementary, although the academic or professional level of knowledge was not considered to be useful or accurate without some level of service user input to inform and shape it.

Eliciting service-user expertise was also seen as an important means of engaging with homeless people and allowing them to open up and feel comfortable in service settings. Sue suggested that being a middle-aged woman with many years of experience of homelessness had often made her feel more knowledgeable than the younger, inexperienced staff at some of the homelessness services. She had avoided using a number of services where she felt the staff lacked an appropriate level of insight and knowledge. Interestingly, service user Greg had attempted to apply for work at an accommodation service, but had been discouraged because his experience of homelessness was seen to be inappropriate for the role. He saw his experience as enhancing his knowledge and ability to work with homeless clients. Unlike the mental health service sector, discussed in the following chapter, the homelessness service sector has not generally moved towards professional consumer roles and there appears to be a distinction between professionalism and lay or personal experience. Service users Jane, Steve and Mike suggested human service professionals should undergo training provided directly by service users as a compulsory part of their formal training to develop their sense of empathy and deepen their understanding of the complex issues they sought to address. Service users Isabelle and Jane indicated only someone who had used the human service system could really appreciate its faults and understand what needed to be changed, suggesting service users “know how to navigate it; they know what's wrong with it” (Jane).
Service-user perspectives on EBP

Service-user experiences of EBP

Service users perceived their ideas, feedback, and experiences as evidence. Service-user expertise – or the values, interests, and preferences of the client – is an essential leg of EBP along with research and professional expertise. It has generally been treated as separate from the knowledge forming the hierarchy of evidence which is research based, although those versions of the hierarchy which include “consumer” opinion as part of the “expert opinion” category on the lowest rung of the hierarchy muddle this distinction (Fraser, et al. 2009).

Interviewees were asked to describe their familiarity with and understanding of EBP. Of the eleven service users interviewed, four were completely unfamiliar with, and not able to provide a definition. Melanie, Greg, Rodney, and Isabelle described EBP as a process of incorporating client or consumer feedback into practice and policy making, whereby the service user was the primary source of evidence. It should be noted, however, the study was biased towards this type of definition because it targeted service users involved in advocacy and representation activities. Three participants offered definitions aligning with popular EBP theories from the literature. Penny was familiar with the term because of her studies in community services. Paul understood it to mean practice and policy making based on best evidence, such as the common ground model of housing which has come about from looking at the evidence from New York programs. Jane had also gained an understanding of EBP through her studies and was mindful of the subjective nature of evidence and the way in which the quality and usefulness of evidence was a matter of perception. She suggested EBP was important, but that evidence needed to be considered holistically in light of the circumstances of
clients in particular situations, which, ironically given her position as an EBP critic, is precisely the intent of EBP.

In contrast, only one of the five service providers interviewed offered a definition of EBP aligning with that found in the literature. Christine had an academic background and was well versed in the hierarchy of evidence. She saw much of what happened in Australian homelessness policy and practice was not evidence based, because it was not founded on methodologically sound research. The other service providers were familiar with the term, but were not clear in their account of what constituted evidence. They cited sources such as client and consumer feedback, internal data collection, program evaluation, and sharing of information with other agencies about what works as examples of EBP.

That most participants were familiar with the term EBP, but inconsistent in their definitions and understandings, possibly arises from the jargonistic use of the term in the human services where it is poorly understood. The definitions offered also suggest the hierarchy of evidence has failed to gain resonance, because it does not account for service-user opinion, professional wisdom, or internal evaluation mechanisms in a useful or meaningful way. Service providers Christine, Pam, and Sylvia referred to the housing first and common ground models as examples of EBP in action, exemplifying the way EBP was programmatically conceptualised in the field. Service user Penny discussed her own research on housing first in order to support her role as a consumer advocate, and Paul discussed the establishment of the Sydney common ground project as an example. These models were discussed in positive terms because they had demonstrated effectiveness overseas. Certain interventions were considered as evidence based because of the availability of research to support them, rather than a view of EBP as a process. In some respects, this view of EBP works against its ability to enhance
decision making and expand service-user choice, because a couple of key models have
gained resonance as being evidence based, though there may be other homelessness interventions for which little evidence is available or widely promoted. Jane expressed her frustration with policy makers:

Their first question is ‘so what is the answer?’ Like they're expecting it's a one-size-fits-all answer and response. There has to be one solution to the problem of homelessness, what is it? Well you know, there is not one solution, we're all different people, different problems at different stages of life. Different reasons brought us into homelessness. Homelessness then created different problems. You can't just provide one solution because homelessness after a period of time becomes a lot more than just houselessness.

Both evidence-based practice and evidence-based policy making need to consider a broad range of diverse alternatives appropriate to localised and individual circumstances.

**Evidence to support accountable decision making**

Service users and providers saw policy and service-delivery decisions to be arbitrary and non-evidence based. Much of the homelessness intervention and treatment work done by government and the community sector services was seen to be based on a crisis response with preference for servicing particular groups of clients, the religious foundations of the agency in the case of faith-based NGOs, and populism in the case of government, maintaining the status quo and resistance to change. While service users were cynical about the extent to which evidence informed decision making and policy making within the homelessness sector, they generally felt it was important and
valuable for services to be developed based on sound evidence. They saw EBP as an opportunity to enhance service accountability and effectiveness. Isabelle suggested making decisions based on evidence and research could counter corruption within the sector and Paul saw EBP as an opportunity to move away from services assuming “they knew best” and instead looking towards externally proven models. While Penny was cognisant of the challenges, such as limited time and resources, for professionals to practice EBP, she was adamant “If they can see something works then make it a policy”. Steve and Laura expressed their hopes services would provide more information about effectiveness and research to support interventions at an individual level, so they could better understand the options available to them and make more informed decisions.

**Participation, information, and evidence in decision making**

**Information sources**

At an individual practice level, service users were generally unsure about why practitioners made certain decisions or why certain service models were in place. Interviewees indicated most services provided very little information about the program or treatment on offer. Gambrill’s (2006b) model of EBP advocated for evidence to be part of a partnered decision-making process between practitioner and client. The best available evidence for various options would be presented to the client to then decide which option best met their unique needs and values. The interview results indicated the reality of service provision in the homelessness sector was a long way from this idealistic notion for a variety of reasons. As indicated earlier, the experience of homelessness is marginalising in Australian society and a homeless person has little
power in the decision-making process. As supported by this study, people have tended
to take ‘what’s on offer’ rather than make a genuine informed choice. On reflecting
upon their most vulnerable times of heightened crisis, service users described needing to
have high levels of trust in professional service providers. Shaw’s (2002) notion of
“proto-professionalisation” (p. 289), whereby the consumer was becoming better
informed about their issues and options available to them, especially through use of
technology such as the internet, only partially holds true with people who have
experienced homelessness. The processes described in the EBP literature suggested a
rational, informed process in which a choice was made between various interventions or
treatment models. Eight of the service-user participants described the importance of
word of mouth in learning about service and treatment options. Fellow service users
were perceived as a trustworthy, relevant, and useful source of information on the
quality and accessibility of services. The decisions about which services or treatments to
accept were not based on evaluations of empirical evidence, but on the opinions and
ideas of a network of peers. Again, the service users saw the knowledge gleaned from
lived experience of homelessness as an extremely valuable source of expertise. It was
certainly the most highly valued resource when seeking services.

Another common source of information to influence decisions about accessing
services and treatment programs, identified by four of the participants, was
recommendation or referral from another service, such as a specific information and
referral agency, council community service, or housing agency. In these instances, the
service users had an established relationship with a particular agency and continually
called on the agency for information. One participant identified her general practitioner
as an important source of information about available treatment options in relation to
her mental illness. Verbal advice and recommendations were clearly favoured. Factors
such as illiteracy, low levels of education, poor access to computers, and lack of available materials meant electronic and hard copy written materials were rarely used. One participant had watched documentaries to learn more about her mental illness. Only four (Penny, Melanie, Paul, and Steve) service users described having conducted their own investigation into the issues affecting them and, in all instances, this came later in the service-seeking process after they had passed the period of heightened crisis. Melanie, who had experienced serious mental illness, said she had gradually developed an interest in her illness and as this interest developed she’d elicited information from her psychologist. Three service users described using the internet as a source of information, but their use was limited by poor access and they generally looked at specific information sites recommended by peers. One had begun to use the internet more frequently as part of her role as a service-user advocate.

While service users, to varying degrees, actively sought information to support their individual service access or treatment, or to support their role as advocates, they did not engage with evidence. This was largely because the professionals they worked with did not involve them in a process of EBP and critical appraisal of the evidence regarding intervention and treatment models was not commonplace in the homelessness sector.

**The limitations on choice**

Isabelle described a frustrating and arduous process of “ringing around” in desperation for hours and days on end to find a service to help with her housing crisis. While highly stressed at the prospect of becoming homeless with her child, and with only a few days left in her existing housing, she was continually referred to the same agency which had already informed her she did not meet eligibility requirements. This was typical of the
service-users’ experiences of accessing human services. There was not a process of rational or evidence-based decision making on the part of the consumer because there were generally no services to choose between. Rather, it was a process of finding a service for which the service user was deemed eligible and taking what was on offer, or else sleeping rough on the streets. Service user Penny described this as a “cookie-cutter approach”, whereby service users were expected to fit in with the existing range of services and to meet certain moulds and stereotypes or risk being seen as problematic or difficult clients. In her case, her assertiveness and drive to be in control of the process of finding housing and stabilising her circumstances was seen as a challenge to a service sector she perceived to dole out housing and support, with low expectations of the capacity of people to be active, intelligent participants in the process.

**Accountability**

An overarching theme, pertaining to the lack of information provided to clients of homelessness services and the lack of participatory mechanisms, was the overall lack of accountability to service users. Service providers and users described the ways in which those services funded by government were accountable for the funds they used through reporting mechanisms. Service provider Sylvia explained the ways in which government-funded services were accountable to government funding agencies through reporting and outcome-based measurement processes. Service users Steve and Paul expressed concern about the accountability of donor-funded charities for their use of resources. However, as indicated by service provider John, “to the extent that there is any type of accountability it's to funders and not to service users”. It was generally perceived there was little to no recourse for service users regarding the effectiveness, appropriateness, and efficiency of services. If a service did not “work” for a client they
could only “walk away” (Steve). Service providers strongly stated they too felt there was little accountability to service users. Tim indicated the sector’s failure to really understand “what’s working” was in part because of its failure to communicate with service users and gain their feedback. Pam saw a dire need for improved data collection on homelessness as a means for holding government and non-government agencies accountable. She saw the collection of data, such as counts of those sleeping on the streets, as essential to monitor the impact of interventions and programs. Further, she saw a responsibility to present this information back to service users in order for them to hold service providers accountable. In this sense, there was a potential role for this kind of data to monitor the effectiveness of interventions and afford a transparent means for stakeholders, including service users, to measure improved quality of interventions and programs.

Most service users were cynical regarding the distribution and management of funds and resources by agencies in the homelessness sector. Service users often perceived policy and programming decisions as arbitrary. Similarly, many indicated decisions about management and use of funds and resources were unclear, unfair, or poorly informed, without a real understanding of what needed to be done. Service user Jane suggested:

I'm not saying services are over-resourced, but if services were more accountable for the way in which they used their resources and gave them out fairly to a range of people rather than the ones they picked and chose [sic], I think that there'd be a lot more successful outcomes out there.

Isabelle, who was now in permanent housing, was still perplexed as to why she’d had such a difficult time getting housing support, believing it was simply because
services “didn’t want to” help her. Service users Steve, Paul, Jasmine, Jane, and Rodney believed service providers in the homelessness sector were not held accountable for the way they spent funds and used resources. As a result, funds were often mismanaged. For most, the only way they saw themselves able to respond to poor service or what they perceived as poor management was to choose not to access a service or to walk away from it. In other words, to vote with their feet. Given that services were often funded according to rates of usage and the power of word of mouth among networks of people with experience of homelessness, there was potential for this strategy to be more powerful than it might initially seem. However, complaint and feedback mechanisms were strongly criticised, because service users believed if they complained they’d be considered troublemakers, endangering their chances of being housed or receiving support. Most participants were reliant on some form of government payment as a source of income and Sue described the fear of payments being suspended if she were to complain to or upset staff. Service user Melanie was also critical of the power agencies such as Centrelink held over service users, indicating people felt like beggars when they needed to seek support and were therefore reluctant to do so, or else became masters at manipulating the system in order to meet their needs.

The concept of an evidence-based model of service provision, whereby clients were part of a decision-making process, including an assessment of the evidence to support one intervention or model of service provision over another, and where the effectiveness of an intervention or model was regularly tested and readjusted, was foreign. Rather, the picture painted by both service users and providers was of a sector responding to crises, in which the service users were frustrated, excluded from real decision making, and treated as recipients rather than partners. They were rarely
consulted as experts with meaningful input to provide to the policy-making and programming process.

**Value of evidence and potential for EBP**

It was difficult to ascertain the perceived potential role for EBP in fulfilling service users’ expectations regarding accountability and informed decision making, given the confusion regarding the concept of evidence. While most respondents saw evidence as any information, data, or knowledge useful to informing, or providing proof to justify a decision, EBP literature perceived evidence as research-based knowledge and clarity regarding its definition was important to understanding and grappling with implementation issues (Gray et al., 2009; Marston & Watts, 2003; Mullen, Shlonsky, Bledsoe, & Bellamy, 2005; Scott-Findlay & Pollock, 2004). However, the ways in which respondents talked about decision-making processes, accountability, and the roles of service users and practitioners did allow for some extrapolation of potential roles and strategies for EBP in supporting participatory parity. Despite their frustration with the system of human services and the apparent absence of EBP (with the exception of one respondent who had a positive experience, but saw others around him struggling) the study was able to explore the perceptions of service users regarding the capacity for EBP to improve their position and the values placed on evidence, given the crisis nature of many of the circumstances in which human services were needed.

Participants, service users and providers, reinforced the notion put forward in the green paper (Australian Government, 2008c) that homelessness human services had failed to comprehensively understand the issues they sought to address and to effectively gauge the success or otherwise of their interventions. Improving the relationship between research and practice was perceived as a potential means to better
understand the issues surrounding homelessness and to holding policy makers and
service providers accountable for their actions and decisions. One of the weaknesses
identified was the failure to acknowledge and accurately define the outcomes sought
through service provision. SAAP data has been a primary source of information to
guide policy and allocation of funds, but is problematic because:

It misses the many thousands who did not approach a SAAP service, those who
use mainstream services, or people who receive a service from a homelessness
service not funded under SAAP. Also, the data collection does not provide
detailed information about the medium and long-term outcomes for those who
receive assistance through specialist homelessness services. (Australian
Government, 2008a, p. 59)

Service providers Pam and Christine reiterated this criticism. Christine was critical of
the over-reliance on SAAP data which was seen to be biased and unreliable because it
could, by virtue of the data collection mechanisms, only reflect back statistics pertaining
to populations targeted for funding. She cited, for example, “the often quoted one, 50% of
SAAP users are women. Well, mmmm, how many SAAP services are there? Oh, 50% of SAAP services are women only services!” SAAP data was not seen to reflect
unmet needs and hard-to-reach populations. Pam was cautious about using international
evidence warning that although the evidence was really important and useful, some
people had felt alienated and concerned it did not apply to Australian circumstances.
Christine was supportive of looking to international evidence, so long as it was rigorous
and transferable. She saw a need for more local research, but was reluctant for the
policy-making and service-provision process to be slowed down while waiting for
evidence to be gathered.
Service user Jane was also highly critical of SAAP data for the way in which it counted “numbers through the door”, rather than measuring “successful outcomes for people who are homeless”, by which she meant transition “into actual housing and housing that was appropriate and suitable and affordable”. Measurement based on ‘numbers through the door’ was seen as unreliable and prone to manipulation, whereby an individual could be exited from a crisis accommodation service, later readmitted and therefore double counted. While moving in and out of crisis accommodation was a poor outcome in terms of housing stability, it boosted the figures for SAAP providers. Service user Isabelle was similarly critical of the way in which agencies used data, indicating she had seen significant levels of corruption and dishonesty in the way data was managed and manipulated. She noted instances where she’d seen services misrepresent data in reports to funding bodies in order to receive more funds or to justify use of resources.

Whether claims of corruption and deliberate manipulation of data are founded or not is not important to this study. What is important is the way service users perceived the homelessness human services sector. The lack of accountability and transparency and the way in which service users were marginalised from participation in decision making left the sector open to this type of perception. And, while not necessarily representative of the broader homeless population, the study showed there were service users within the homelessness sector who were astute and savvy in regard to the failures of the sector’s accountability mechanisms.

Service users tended to believe it was important for services and treatments to be based on accessible evidence, although understandings of evidence varied and most considered service-user input as a crucial component of evidence. Isabelle saw being evidence based as a means to counter the corruption she had observed in the system.
She and others suggested EBP as a means to address the arbitrary nature of decision making and the over-reliance on the whim, ability, and inclination of individual workers within the system. Service users Laura and Steve were very interested in the notion of EBP because they wanted to know more about the alternatives available to them, and more importantly, *why* an intervention may or may not work for them. Having moved from periods of crisis to relatively more stable housing, they had reached points where they were much more enquiring and confident in their approach to service use, but were unsure how to go about this. Service user Paul saw some shifts towards EBP in the sector, particularly in looking to international models of practice, in the face of a mentality of maintaining the status quo. He saw an increased use of evidence as important to challenging and improving standards, stating “we’ve got to get away from this attitude of ‘we [service providers and policy makers] automatically know what’s best’”. Service user Sue was similarly enthusiastic about her encounters with EBP, having attended a national housing conference where international models had been presented. She had heard about the success of certain programs overseas and saw it was really important for Australia to use this type of information to develop its own programs. Service user Penny was mindful of the challenges for EBP, particularly the limited time available to workers and the limited funds within the sector. However, she also felt strongly if there was evidence showing a program or intervention could be successful, it should be implemented.

The study showed the users of homelessness services supported increased use of evidence to inform practice and policy making, although given the dearth of examples of EBP in their experience of service use it was difficult for them to suggest what an effective model might look like. Factors such as the relationship with the worker, accountability, and service-user expertise would need to be incorporated to reflect
service-user concerns and priorities for effective service provision. Failings of the system perpetuated and also resulted from the failure to treat service users as partners and equal participants at individual levels of treatment and representative or policy levels. What role then could be seen for service users in future modes of EBP and how could their participation be enhanced by such models of practice?

**Role for service users in a participatory model of EBP**

**Roles in research**

All the service users, except one who was a new member of his service-user group, had participated in research-related activities. Some had, as part of their work in service-user groups, designed and conducted surveys. As a group they had decided on survey questions based on their knowledge of homelessness and they had engaged with their networks of people with experience of homelessness to access participants for the surveys. Surveying had been undertaken to help guide their advocacy activities and for use by their parent or support agencies in their work. Some participants had conducted surveys and interviews for other researchers, acting as mediators between researchers and research participants. At times this was conducted alongside a worker or a researcher, particularly in cases where additional assistance was required with reading and writing, and at other times service users went out on their own to collect data. In these cases research participants were sourced at accommodation services or in areas known to be popular among homeless people. One service user had acted as an adviser to the local street count, helping those administering the survey to shape the process and identify target locations. One group of service users had provided advice to an academic researcher examining a specific facet of homelessness. They had given direct input
about their experiences of the issue, provided guidance about how to structure the research in a sensitive and appropriate way, and helped the researcher make contact with research participants.

Service users described these research experiences in very positive terms. They indicated their knowledge and understanding of the issues around homelessness had allowed for more accurate research results reflecting the reality of the situation. They felt they were able to glean honest information from homeless people because of the shared experience and they were more likely to be trusted than an academic, worker, or researcher, supporting the notion gatekeepers play a crucial role in developing the relationship of trust between researcher and socially excluded participants (Emmel, et al., 2007). Most of the service users interviewed saw this type of research activity as a valuable and important part of their role as a service-user advocate or representative.

The role of the service user in sourcing evidence and acting as a conduit between researcher and research participant was a tangible manifestation of their role in research and evidence-based processes, with clear examples to illustrate how this role had been played out. However, the stronger theme recurring in all service-user interviews within the homelessness case study was the ‘service user as expert’ role. This was a role more difficult to define in tangible terms and it was discussed as a concept or a principle, rather than a defined role.

**Finding a place for service-user expertise in EBP**

Service users saw the knowledge they had gained through their lived experience of homelessness as useful, affording them a unique and crucial insight. They saw their lived experience as evidence and as intrinsic to EBP. Rodney captured this sentiment: “It's a matter of you've got to have been there to have understood it”. Most made direct
statements about their knowledge as expertise such as Jane’s comment, “the people who have experienced homelessness, they’re the experts in their field. And they know the system. They know how to navigate it. They know what's wrong with it”. Service users also made direct statements about the nature of their knowledge as evidence, such as Melanie who stated the people who use the services were “where the evidence is”. Penny indicated while service-user input and opinion was a crucial form of evidence, it should not be treated in isolation and other, more scientific and even clinical types of knowledge were also important.

Service providers supported the notion that service users were a crucial source of knowledge to inform and guide practice and policy. However, they were generally in agreement service-user knowledge constituted only one part of the evidence base. Tim saw consulting directly with affected people or service users as part of an evidence-based approach and the first step in gathering evidence, during which he would also consult more traditional sources, such as journals and professional experts. Similarly John indicated, “we use people's stories as the 'evidence' but we recognise that it doesn't paint the full picture”, citing sources such as Australian Institute of Health and Welfare, and Australian Bureau of Statistics as other useful sources of evidence. None of the interviewees mentioned key EBP resources such as Cochrane Collaboration or Campbell Collaboration as sources.

So, at the representative level, there was a general perception service users participating in advocacy or representative roles had a valuable role to play in supporting researchers to construct sensitive, appropriate methodologies, acting as gatekeepers between researchers and hard-to-reach participants, collecting data, and engaging with research as a tool in advocacy work. It was strongly felt service users
were a source of vital and unique expertise and ought to contribute to the building of an evidence base in some way.

But what role, if any, could service users play in evidence-based process at the individual level, i.e., at the level of individual interactions between service users and practitioners?

**An individual, process-oriented approach to EBP**

It was difficult to gauge the potential for individual service users to take a role in enhancing or promoting more participatory models of EBP at a practice level, because the concept was unfamiliar and most had not experienced the type of interaction outlined by Gambrill (2006b).

There was little indication of evidence use, although there was an indication that information was helpful and powerful. Some service users had begun conducting their own investigations into the issues affecting them, but only one was using this information as a tool to support decision making about treatment options and this was in relation to her mental health issues. For those others doing their own investigation it was related to building an understanding there were other people living similar experiences or using the information as part of their new roles as advocates and representatives so other people facing the experience of homelessness would have an easier experience of the system. All but one of the participants were housed at the time of interview, although housing stability would be an ongoing issue for many. The experience of gaining access to stable housing had been about taking what was on offer and the skill of the service user was seen to be in knowing how to navigate the system of human services and to comply with what was presented as a complex and often confusing array of criteria. The disparity in power between government and non-
government agencies providing housing and accommodation services and the service
user, who often desperately needed the service on offer, gave the service user few, if
any, mechanisms by which to hold the service provider accountable and certainly had
no means by which to challenge the validity of the evidence base on which decisions
were made or to suggest alternatives.

Participants were ambivalent about the notion of service providers offering more
information about effectiveness of treatments and service models and the evidence base
informing them. Most were keen for greater transparency to understand how decisions
were made, to see that decisions were made fairly, and to have guarantees that funds
and resources were distributed effectively. They believed it was important for service
models to be informed by rigorous research, but did not necessarily want to see this
research themselves. The focus was on the ability to have trusting relationships with
agencies and workers. The only mechanisms participants really felt were available in
terms of making choices as part of the service-seeking process, were the ability to walk
away from a service failing to meet expectations, use the strong system of word of
mouth to spread news of poor service among peers, and hope a reduction in service use
would have flow-on effects to the funding for the agency.

The trusting relationship was central to most participants’ descriptions of a good
service. One participant, Penny, was able to describe an experience similar to the
partnership model of EBP described by Gambrill (2006b), in which a caseworker first
worked with her to establish goals and aspirations, looked jointly at the range of options
available to achieve these aspirations, and continually check back with Penny to
ascertain progress and readjust the case plan. While there was no evidence presented to
Penny to support her role as a decision maker in this process, it was the only case cited
during the interviews where the participant was able to describe active participation in
making choices about the treatment and services available in partnership with a worker. Casework is a dominant model of service provision within the homelessness sector, although its guises vary greatly and it may be practised by social workers, youth workers, community support workers, psychologists, or any number of professional or nonprofessional workers. The implication of the study’s findings is that service users expect caseworkers to provide interventions and services based on reliable research. They want to be part of a partnered approach to decision making and understand how and why decisions were made. However, they did not necessarily want to read a lot of material.

Service-user participation groups in the homeless sector have been largely supported by legal agencies whose imperative for participation was based on a human rights model. As such there was the risk of bias towards notions of participation as a human right and this certainly emerged in the interviews with service users. However, one service user interviewed had participated under a different model of advocacy, and he also considered participation as homeless people’s “right, if not their duty to stand up and be counted” (Paul). Under Fraser’s (2001, 2008a) notion of participation this includes the right to access economic, legal, and political resources, beyond the right to simply have a voice. Service provider Christine was adamant many of the responses to homelessness were insufficient and ineffective in addressing the fundamental issue of homelessness, stressing “being well meant in the homelessness service sector seems to be enough”, with supply of emergency provisions such as temporary accommodation, clothing, and food a focus to the detriment of resolving long-term housing issues. She reinforced service users’ claims there was no choice in service provision because people were desperate and needed to take whatever they were offered. An evidence-based approach to resolving homelessness would redefine the notion of a successful outcome
with consideration to full and meaningful participation and allow people to be active partners in defining their goals, rather than slotting in to existing programs.

**Conclusions**

Australian homelessness policy, particularly at a national level, set a high standard for reforming the sector and intrinsic to this reform were notions of participation, social inclusion, and evidence-based decision making. But the reality at the point of service use highlighted the challenges for reform in an environment where vulnerability, powerlessness, and subordination were heightened by the complexity and intensity of the experience of homelessness, as summarised in Table 5.1.

**Table 5.1 Comparison of policy intent and service-user perception**

<table>
<thead>
<tr>
<th>Policy intent</th>
<th>Service-user perceptions</th>
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</thead>
<tbody>
<tr>
<td>Economic and social participation of all citizens</td>
<td>Treated as non-citizens</td>
</tr>
<tr>
<td></td>
<td>Ongoing reliance on social welfare payments with limited employment opportunities</td>
</tr>
<tr>
<td></td>
<td>Social participation impeded by stigma and shame attached to homeless identity</td>
</tr>
<tr>
<td></td>
<td>Little power over decision making, little choice</td>
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<tr>
<td>Improve the evidence base to inform policy making</td>
<td>Evidence base meaningless without service-user input</td>
</tr>
<tr>
<td>and service delivery</td>
<td>Emergence of housing first and common ground models demonstrated improved use of evidence</td>
</tr>
<tr>
<td></td>
<td>Service level decisions seemed arbitrary and non-evidence-based</td>
</tr>
<tr>
<td>Improve cost effectiveness of interventions</td>
<td>Misuse of resources and funds</td>
</tr>
<tr>
<td></td>
<td>Priority on keeping services operating rather than resolving homelessness</td>
</tr>
<tr>
<td>Service user input to inform state and regional</td>
<td>Initial optimism about Premier’s Council waning</td>
</tr>
<tr>
<td>actions</td>
<td>Service providers speaking on behalf of service users (not true participation)</td>
</tr>
<tr>
<td></td>
<td>Tokenism</td>
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</table>
Users of homelessness-related human services provided a pertinent case study because they had experienced significant disparity in the opportunities afforded to them within the human services sector, and within a society where the experience of being homeless and its associated issues were seen as deviant. The service users interviewed were passionate about advocating for the rights of homeless people and about improving the service system that had been a source of confusion and anguish. They were knowledgeable about the system, insightful regarding issues of homelessness and participation, and eloquent in their advocacy and representative skills. However, their skill and expertise were yet to be properly harnessed within the sector. The infancy of service-user participation in the homelessness sector brought the promise of exciting and important opportunities to recognise the rights of homeless people and improve the way that services were designed and delivered. However, advocates of participation saw that others in the sector perceived participation as a threat to the status quo and to the paternalistic nature of homelessness service provision.

The paternalistic and crisis modes in which homelessness services were delivered meant there was little demonstration of accountability, particularly accountability to the users of homelessness services. Accountability to funding bodies, especially government agencies, had increased, but there was significant cynicism indicating this type of outcome-focused reporting and accountability system had led to manipulation of statistics and actually been detrimental in supporting long-term, sustained housing outcomes because funding was related to numbers through the door.

Service users saw decision-making processes were arbitrary, and there was support for practices such as EBP that would require policy makers and service providers to demonstrate the processes and rationale behind decisions. However, there was significant caution regarding EBP, largely due to confusion about its meaning.
Models, such as housing first, which were supported by empirical research, were gaining support in Australia, and were referred to as examples of evidence-based practices. This indicated an enthusiasm in parts of the homelessness sector to look to research to inform policy and practice, but because the process of EBP was not understood within the sector, it had not moved beyond the notion of a few set practices with some research backing.

The dilemma for implementing EBP in the homelessness sector was the challenge for evidence to be reconciled with service-user expertise which was seen to be potentially highly valuable and useful in shaping policy and practice. Service users saw their expertise as a type of evidence and also perceived a role for themselves in contributing to building the evidence base, including participating in research activities. The network of service users as a source of information, guidance, and advice, mainly through word of mouth, was central to the way service-user expertise affected patterns of service use and navigation of the system.

At an individual level, service users had encountered very few opportunities for participation or EBP in decision-making processes and had, instead, felt at the whim of a complex, confusing, and arbitrary system of human services. The conceptualisation of EBP as an informed, collaborative framework for decision making (Gambrill, 2006b) was far removed from the actual experiences of users of homelessness services, who either took what was on offer, or walked away from a service at times of heightened crisis. In short, homelessness service users, in identifying the disjunct between policy aspirations and actual experiences of EBP and participation, offered insight into the importance of models of practice and policy making which captured the value of participation at representative and individual levels and which simultaneously demonstrated accountability and rigour.
CHAPTER 6

Case Study: Mental Health

Internationally users of mental health services have been pioneers of consumer participation movements and leaders in advocating for enhanced collaboration and partnership between policy makers, practitioners, clinicians, researchers, and service users. The prevalence in policy and program documents of concepts such as recovery, the client-centred approach, consumer involvement, collaboration, partnership, consultation, shared decision making, and consumer advocacy is indicative of the way in which mental health consumer participation has achieved mainstream currency. Nevertheless, the experience of participating in, and sustaining a strong, decisive role in the mental health service sector will be shown to be potentially highly valuable, but fraught with challenges, limitations, and ongoing claims of tokenism. Likewise, the concept of EBP within the mental health service sector is fairly strongly established, largely due to the proximity to, and cross-over with, health and medical models of practice, such as evidence-based medicine. Depending on the understandings and perceptions of EBP, whether seen as a specific approach or clinical process, it is seen to have capacity to enhance accountability, trust, and recovery, or alternatively, to reinforce bias towards pathologised notions of mental illness. The concept of service-user expertise and the value of lived experience are central when considering the role service users might fruitfully play in participatory modes of EBP. However, as this chapter reveals, aspirations to full, equal participation need to be tempered with the realities associated with the experience of periods of severe mental illness. At the most severe end of the mental health continuum, psychosis severely impairs judgement and
social functioning. Hence mental health service users need to be understood as complete, complex individuals for whom mental illness is only one component of their lives, albeit one that, at times, severely reduces their functional ability. Having said this however, these are not factors prohibiting equal participation. Rather they are strong reasons for advocacy for redistributive and restorative mechanisms to minimise disruptions caused by mental illness, underlining the importance of service-user participation. As already noted, Sackett et al.’s (1996) original definition of EBP highlighted the importance of service-user values, interests, and preferences and, to this extent, was participatory. In a context such as mental health, where group interests are mindful of the diversity and complexity of individual experience, the need for service-user involvement becomes paramount, especially in an environment where people with mental illness are often treated as a homogeneous group and somewhat ineffectually labelled ‘mental health consumers’. The long history of service-user involvement in mental health attests the desire to be treated as participants in a decision-making process (the participatory service-user model) rather than solipsistic individuals with choice (the individualistic consumer choice model).

Service-user participants in this study, when asked to describe their experiences of mental health related service use, spoke of a range of services that spanned health and human services and were provided by government, private, community-based and peer agencies. While federal and state policy frameworks and funding models delineate service types and service provision such that most are the domain of the health sector and others are the domain of the human services sector, it appears that these delineations are meaningless and irrelevant to the service users themselves. In light of this, the types of service experiences discussed in the study are broad and vary across the service users, with some focussing heavily on experiences of hospitalisation, others
reflecting on use of community-based counselling, accommodation and social support services and most describing use of a diverse mixture of services that include medical, welfare, housing, peer, social skills, rehabilitative, psychological, recreation, therapeutic and family-focused support options. The diversity and complexity of what constitutes a service use experience for a person with mental illness is important to note, because it means that approaches to structural reform and attempts to enhance parity of participation need to be broad and cross-over funding stream and agency-based demarcations.

As outlined in Chapter 4, the participants in this case study comprised service users engaged in interviews (n=11), service users engaged in focus groups (n=4) and service providers engaged in interviews (n=6). The service-user participants were recruited through advertisements in newsletters and bulletins published by mental health consumer advocacy groups. Most had been involved in structured, often paid roles within formal consumer groups, many within health services, where their aim and role was to improve the experiences of other service users within the system and enact a process of change from within the system. Some participants saw themselves as falling well outside these structured participation mechanism because their illness precluded them from some formal activities or they lacked the motivation, confidence, education, or personal characteristics they perceived to be important in these types of roles. The impetus for service-user participation and consumer advocacy was driven largely by reactions to a service system seen to be at best ineffective and at worst abusive, negligent, and lethal. The ways in which service users participated were influenced by their perceptions of the service system as distrustful and lacking the capacity or willingness to adequately meet the needs and aspirations of mentally ill people.
The service providers were drawn from organisations targeted for participation after discussion with service users about key agencies and after reading literature and newsletters relevant to the sector. Because both service-user and service-provider interviewees self-nominated, there was a tendency for participants to value service-user participation, although their perceptions about what constituted effective participation varied.

Overall, the mental health case study presented below exemplifies service-user demands for dynamic, individualised, and respectful participatory models of practice and policy making which include participation at various levels, from individual client treatments or interventions to representative structures within organisations, governments, and broader society.

**Literature overview: EBP, participation, and mental health**

The literature and policies pertaining to the participation of service users, at treatment, representative, or advocacy levels in Australia, generally referred to “mental health consumers” (for example, see Australian Government, 2009b; Browne & Courtney, 2006; Griffiths, et al., 2004; Honey, 1999; Lammers & Happell, 2003; Mental Health Consumer Outcomes Task Force, 2000; New South Wales Consumer Advisory Group - Mental Health Inc, 2008; Tobin, Chen, & Leathley, 2002). It was a contentious label, often seen as reductionist and overly focused on the economic and individualistic transactions of service delivery, but also perhaps a functional and practical term at least implying certain rights and choices (Craze Lateral Solutions, 2010; Pinches, 1998).

Bolzan and Gale (2002) advocated a shift from consumerism to social citizenship, noting the way mental health support group participants in Australia challenged the individualistic underpinnings of consumerism by advocating collectively for equal
access to quality services. In defining their own needs and working towards partnership models of service delivery, they also suggested mental health support group participants contested the consumerist relationship between service provider and service user.

The term ‘survivor’ was used in some international literature to describe the status of living through mental illness and surviving a mental health system often experienced as abusive, neglectful, disrespectful, and damaging (Lindow, 1999). The 1993 Australian Report of the National Inquiry into the Human Rights of People with Mental Illness, also known as the ‘Burdekin Report’, in many respects validated the perception of the mental health system as something to be survived, noting the discrimination, deprivation of rights, and harmful practices occurring within the system which were often more damaging than the mental illness itself (Burdekin, Guilfoyle, & Hall, 1993). This was an important notion because it highlighted a common sense of distrust, anger, and frustration with the health and human service system. Service users saw their fellow service users as more compassionate, trustworthy, and expert allies than professionals, hence the importance of participation within the mental health sector. Further, the problematic tendency to impose blanket labels on people experiencing mental illness who had accessed, or who were eligible to access, mental health services, denied the heterogeneity of these groups of people and undermined the dangers of approaching this type of study without due respect for the diversity and individuality of participants.

While there were examples of professions like social work engaging in the discussion about the value of consumer participation in the mental health sector (Cowling, Edan, Cuff, Armitage, & Herszberg, 2006), much of the Australian literature regarding the participation of consumers in mental health policy and service provision came from psychiatry and mental health nursing perspectives.
The Australian literature generally agreed, while there had been significant claims made regarding improved levels of consumer participation and a public policy rhetoric on the inclusion of consumers in decision making at all levels, actual improvement in participation on the ground was slow and many efforts at participation were considered ‘tokenistic’ (Browne & Courtney, 2006; Browne & Hemsley, 2008; Goodwin & Happell, 2006; Honey, 1999; Kidd, Kenny, & Endacott, 2007). There appeared to be support for the notion of service-user participation in mental health services – and generally this was seen as a positive move, which had created the expectation, by government and by service users themselves, that mechanisms would be put in place for the inclusion of mental health consumers in decisions regarding mental health service provision. Nevertheless, the attitudinal and structural changes required to redress power imbalances and overcome stigma were slow, creating a divergence between policy aspirations and practice realities (Honey, 1999; Kidd, et al., 2007; Lammers & Happell, 2003). Kidd et al. (2007) explored the perceptions of clinicians and consumers in rural mental health services and found a lack of clarity around the concept of consumer participation, what it meant and what it looked like in practice. Further, poor definition regarding the roles of consumer participants had made the implementation of initiatives for consumer involvement difficult. While clinicians and consumers attached value to the unique expertise derived from lived experience, barriers – such as remuneration for participation, funding to resource participation strategies, and fitting participatory activities into existing structures – made the implementation process challenging. Other Australian studies examining mental health consumers’ experiences and perceptions of participation similarly concluded participation was important, but actual availability of opportunities and ways in which those opportunities were structured belied the political and organisational rhetoric on the importance of
consumer participation (Goodwin & Happell, 2006; Lammers & Happell, 2003; Tobin, et al., 2002). Goodwin and Happell (2006) found consumers valued respect, encouragement, and collaboration as fundamental components of participative strategies and were highly cognisant of systematic barriers to participation. Interviews with mental health consumers in Victoria revealed the critical importance of heterogeneity, suggesting participation mechanisms ought be diverse and cater to individual levels of functioning, choice, and circumstances (Lammers & Happell, 2003). As corroborated later in this chapter, Lammers and Happell’s (2003) study suggested the willingness to participate was influenced strongly by the consumer’s ability to function at a particular time, hence much consumer participation intentionally involved high-functioning, well-educated consumers. Tobin et al.’s (2002) attempts to compare consumers’ understandings and experiences of participation across two mental health service sites, one where consumer participation had been enthusiastically adopted for a number of years and the other where limited participation strategies had recently been introduced, illustrated some of the fundamental issues with this type of research. First, there was quite a high rate of refusal to participate in the study. Secondly, the levels of familiarity with the concept of consumer participation, across both sites, were low. Thirdly, their efforts to adopt a participatory methodology and employ consumers to act as interviewers and scribes for the study had positive implications for encouraging participants to share information, but also compromised the reliability of the data. The Australian studies generally conceptualised consumer participation as an active role in decision making in collaboration with practitioners, wherein consumers exercised choice over service use decisions and their roles as a consumer representatives giving input into policy or service development decisions. Note that the term ‘consumer’ is
used to reflect on this literature, as this was the terminology generally utilised by the studies’ authors.

McCallister and Walsh (2004) examined the value of “consumer voices” through the “politics of difference” (p. 24), exploring the challenges for workable participation mechanisms where there was major divergence in the perspectives and power relationships between staff and clients. Ultimately, they asserted, consumer participation could be improved if power relationships were taken into account, effective coalitions were formed, projects were planned effectively, and parties engaged in open dialogue and were outspoken about differences.

There was a wealth of international literature related to EBP and evidence-based practices in the mental health sector given its proximity to evidence-based medicine and fields such as psychiatry where EBP was a more established and accepted part of practice (Bond et al., 2001; Drake, Merrens, & Lynde, 2005; Norcross, Beutler, & Levant, 2006). Various studies on the implementation of EBP, particularly in social work, indicated a similar lack of recognition for EBP as a process (Wharton, 2009). This was also confirmed in the Research Institute for Social Inclusion and Wellbeing survey of Australian social workers. The Cochrane Collaboration (2010) featured over 150 reviews pertaining to the treatment of schizophrenia, most of which pertained to medication-based interventions, but which also included topics, such as case management and cognitive therapy-based interventions. There were also reviews on depression, anxiety disorders, counselling interventions, and a myriad mental health related facets. Since it was not the intention of this study to examine evidence-based practices per se, only limited examples from international literature reflecting the key influences on the Australian approach to EBP in mental health were included, thus maintaining a more concentrated focus on Australian sources.
As is shown in the analysis of in-depth interviews below, understandings of EBP varied greatly, with significant resistance to the medicalised model which was seen to overlook individualised mental health goals and outcomes. The influence of the recovery movement was strong throughout the interviews and was often the source of concern regarding the appropriateness of evidence-focused approaches. As an example of the international literature drawing together notions of recovery and EBP, Davidson, Drake, Schmutte, Dinzeo, and Andre-Hyman (2009) described the tension between the two approaches:

This cursory overview of the guiding principles of recovery-oriented practice and evidence-based medicine – both of which assume that people have a right to make informed decisions about their own care – would seem to suggest that the two are quite compatible. Why, then, do questions persist about the relationship between the two? (p. 328)

Despite these tensions the recovery framework and EBP share important principles relating to respect and accountability. Furthermore, according to Davidson et al. (2009), the recovery model is actually supported by evidence. Their conceptualisation of EBP was very much in line with early definitions of Sackett et al. (1996), involving the critical analysis of, and openness to, the best available evidence. EBP sought to do no harm and achieve informed decision making taking into account client circumstances, values, and preferences. Importantly, both EBP and recovery were processes.

The growing mainstream support for a recovery-oriented model was testimony to the strength of the mental health anti-stigma and anti-discrimination movements in the United States in the 1990s, the model having emerged, or perhaps re-emerged, after a hiatus in which the deficits-focused medical model dominated. The experience-based
recovery model contrasts strongly with the professional expert-based medical model (Roberts & Wolfson, 2004) with the former possibly influenced by the social model of disability derived from the consumer movement within the disability sector (Ramon, Healy, & Renouf, 2007). Ramon et al. (2007) traced the emergence of the recovery model within Australian mental health suggesting it arose in the service-user discourse in the 1990s, primarily in relation to psychosocial rehabilitation rather than clinical services. McGorry (1992) discussed recovery and the value of collaboration between psychiatrists and patients in the early 1990s and is cited as a major influence on building the legitimacy of the collaborative recovery model in clinical services where psychiatric treatment was bolstered by psychosocial support (Ramon, et al., 2007). McGorry’s Australian of the Year award in 2010 perhaps attested mainstream acceptance of the recovery model, service-user participation, and consumer expertise (National Australia Day Council, 2011).

While, from the literature, consumer participation has played a role in shaping policy and services towards service-user choice at the individual level, its role in research or generating an evidence base was less clear. The recovery literature referred to patients or consumers as experts on their own illness, thus establishing the importance of service-user expertise at the individual treatment level (Browne & Courtney, 2006; McGorry, 1992; Mead & Copeland, 2000; Ramon, et al., 2007; Roberts & Wolfson, 2004). Similar recognition was evident in the international literature in discussions on consumer participation in mental health research, the growth of the strengths approach aligning with empowerment principles, and the rise of EBP (Beresford, 2007; Faulkner & Thomas, 2002; Gould, 2006; Gould, Huxley, & Tew, 2007; Rapp, Shera, & Kisthardt, 1993; Trivedi & Wykes, 2002). While there was some
recognition of the potential value of user involvement in mental health research in Australia, evidence of implementation and publication of such practices was limited.

In 2004, the Australian National University hosted a national workshop on the participation of consumers in mental health research, which established draft principles to guide improved consumer participation or involvement in research, appropriate resourcing, training, and support, and the dissemination of research findings back to consumer participants (Griffiths et al., 2004). Mental health consumer advocate Epstein (1998, 2004, 2005; Wadsworth & Epstein, 1998), stood out as a significant contributor to, and promoter of user-led models of research. She believed consumer participation in existing research strategies was not enough. Rather, effective consumer-perspective research required restructuring the way research was funded, designed, conducted, and disseminated. The scoping study into a national peak consumer body identified research as a key program area for such a body, which might include research into key issues and concerns as identified by consumers and researching effectiveness of consumer-run services (Craze Lateral Solutions, 2010).

While the national and international literature recognised the importance of consumer participation and EBP, it also highlighted the challenges arising from a reluctance or limited capacity to fundamentally restructure the way mental health policy was designed and enacted and the way programs were designed, funded, delivered, and evaluated.

**EBP and participation in federal and New South Wales mental health policy**

In Australia, broad policy frameworks and budgets for mental health services are determined by the Australian Government through the federal Department of Health and
Service provision – and state-wide policy direction and funding parameters – are provided by state and territory governments through their various departments of health. However, the actual implementation of policy and service delivery occurs at a regional level through Local Health Districts (previously known as Area Health Services). These services include acute and clinical interventions as well as a range of community-based options. In addition to the public provision of mental health services, the private health system provides mental health clinical services. There is also a plethora of non-government, community-based agencies providing diverse mental health services, including, but by no means restricted to, supported accommodation, recreation, counselling, therapeutic interventions, family, carer, and peer support, and information and referral. Most non-government community-based agencies receive federal and or state government funding to support their provision of mental health services, generally under defined program areas. Others are funded through membership fees, donations, and philanthropic trusts. Many receive a combination of government and non-government funds. The mental health service sector engages a diverse range of professionals from medical, allied health, human service, social work, and community development related fields. Given the breadth of services and the diversity of funding types, it is clear the mental health service sector in Australia is complex, characterised by a mainstream health-oriented public system supported by multitudinous private and community sector services varying from generalist to specialist. The key policy documents utilised for this policy analysis included:

1. Federal government: *Fourth National Mental Health Plan, National Mental Health Policy* and *Ten Year Roadmap for National Mental Health Reform (draft for consultation)*
2. New South Wales government: *New South Wales: A New Direction for Mental Health, Aboriginal Mental Health and Wellbeing policy, Multicultural Mental Health policy*, and *New South Wales Charter for Mental Health Care in New South Wales*


**National – federal - policy agenda**

The *National Mental Health Strategy* is the federal policy framework for the mental health sector, within which various plans and policies function to enact the strategy. In 2008 health ministers from across Australia endorsed the *National Mental Health Policy* (Australian Health Ministers Conference, 2009). The *Fourth National Mental Health Plan* articulated the implementation strategies and action priorities emerging from this national policy (Australian Government, 2009b). In early 2012 the federal government released the draft *Ten Year Roadmap for National Mental Health Reform* (Australian Government, 2012), which outlined five key areas for reform agreed to by Council of Australian Governments (which includes state, territory and federal governments). Development and improved utilisation of evidence was a fundamental component of the federal policy, which suggested “that the approach for any group should be based on the best available evidence for that group and tailored to their particular needs” (Australian Health Ministers Conference, 2009, p. 9), hinting at the importance of an approach to EBP which considers the unique context of an individual, or in this case, groups of individuals. The approach to building and using the evidence base recognised the value of a participatory mode of EBP in stating, “A variety of stakeholders, including people
with mental illness and their carers, should be involved in research and evaluation activities” (Australian Health Ministers Conference, 2009, p. 26). Further, the *Fourth National Mental Health Plan* suggested increasing the employment of consumers and carers in clinical and community support roles as a strategy for achieving quality improvement and innovation, including the implementation of evidence-based models of care. Similarly the draft *Ten Year Roadmap for National Mental Health Reform* (Australian Government, 2012) indicated, in highlighting the need to improve quality of services and ensure services are evidence-based, that improved data collection and expanded workforce, specifically including peer workers, were important.

The principles and actions within the national policy documents suggested connections between service-user participation and EBP were being recognised by policy makers within the mental health sector. The priority of an evidence-based approach to mental health service provision also recognised the disjunct in producing an evidence base and actually implementing practices supported by evidence, noting the need to look to models such as the Cochrane Collaboration and National Institute for Health and Clinical Excellence in the United Kingdom (Australian Government, 2009b). The translation of research into practice was seen as poorly coordinated, inappropriately targeted, and generally lacking. The terms ‘evidence’ and ‘evidence-based’ featured frequently in the policy documents, but there was little critical analysis of the concept of evidence or EBP and no explanation of the meaning given to these terms by the policy authors. For example, looking to “objective evidence” (Australian Government, 2009b, p. 59) was proposed as a means to overcome arbitrary methods of setting targets. Objective evidence was considered that which was based on local and international research, best practice guidelines, and expert and stakeholder opinion. It was this somewhat naive assumption regarding the neutral or objective nature of
evidence that was problematic for EBP’s critics, who saw evidence as often highly politicised, biased, and weighted towards particular modes of research (Buetow & Kenealy, 2000; Glasby & Beresford, 2006; Hammersley, 2003; Marston & Watts, 2003; Young, Ashby, Boaz, & Grayson, 2002). It is important to note the way evidence was described in these national policy documents was not in accord with the notion of EBP as a process, but was concerned more with the determination of evidence-based practices and the increased implementation of methods of treatment and interventions verified by research to be effective. In the draft ten-year roadmap it was suggested that a key monitoring and reporting function would be “Building the evidence base for service improvement and innovation, including sound evaluation where new interventions and approaches are being employed, and translation of research into best practice guidelines” (Australian Government, 2012, p. 36). Components of the national policy documents reflected a promising approach towards EBP, which recognised the value of service-user input and the importance of conceptualising research and practice as connected processes. However, in failing to clarify the meaning of evidence, to distinguish between processes and guideline approaches or to address the potential shortcomings of EBP, the notion of building and using the evidence base is relegated to jargon; a vague and meaningless catchphrase.

Key direction three, of five key directions contained within the draft ten-year roadmap, indicated the emphasis on participation within Australian mental health policy, seeking to put “consumers and carers at the heart of services and supports” (Australian Government, 2012, p. 22). It highlighted the importance of opportunities to enhance participation in work and referred to importance of consumer involvement in decision making and recovery approaches, as well as using the terminology of the “person-centred approach” (Australian Government, 2012, p. 22). Strategies to achieve
this level of participation included representative activities such as the establishment of a national consumer organisation and individual approaches such as increased shared management and self-directed care to ensure greater control over treatment decisions. The *National Mental Health Policy* claimed to “support a vision of a seamless and connected care system which is consumer focused and recovery oriented and where people are supported to engage with the community and participate to their full potential” (Australian Health Ministers Conference, 2009, p. 7). Such a policy aspiration encapsulated a model of participatory parity, in which the system flexed to meet the personal goals, values, and needs of individuals and in which the individual’s notion of wellness and recovery was highly individualised and respected. Participation was conceptualised at a representative or advocacy level, with a focus on the importance of employing consumers and carers within mental health services, and at an individual level where the client should be at the centre of decision-making processes. Participation was not only about participation in processes related to the experience of mental illness and service use, but also about equal access to the full range of opportunities within the wider society, as per the notion of social inclusion. Within the *Fourth National Mental Health Plan*, “Social inclusion and recovery” (Australian Government, 2009b, p. iv) featured prominently as the first of the five priority areas. Actions to achieve social inclusion and recovery included programs to address stigma and discrimination, enhance consumer choice, develop “wrap around” (p. 24) service provision (providing a range of services and supports through one coordinated process tailored to the individual), integrate services and programs, and institute a recovery-oriented culture. The language of consumer involvement was frequently used, with propositions that consumers and carers “should be actively engaged at all levels of policy and service development … [and] fully informed of service options, anticipated
risks and benefits” (Australian Government, 2009b, p. 13). The value of consumer input and insight was regaled, such as the notion “consumer and carer experiences and perceptions” (Australian Government, 2009b, p. vii) were integral to reporting mechanisms to monitor quality and innovation and the intention to improve the accountability of services by making performance information available to consumers. The employment of carers and consumers was also a priority. Recovery and self-determination were seen as fundamental principles for rolling out the national policy, recognising these were principles adopted and promoted by many community organisations and consumer advocacy groups, which needed to be incorporated in public and private clinical services. Recovery was defined as:

A personal process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It involves the development of new meaning and purpose and a satisfying, hopeful and contributing life as the person grows beyond the effects of psychiatric disability. The process of recovery must be supported by individually-identified essential services and resources (Australian Health Ministers Conference, 2009, p. 31).

In 2008 the Australian Senate Standing Committee on Community Affairs (2008) endorsed the value of recovery as a fundamental principle, identifying it as one that had permeated mental health policy and service delivery in Australia. However, it also cautioned there were gaps between the policy rhetoric and service delivery so recovery was little more than a buzzword and recovery-oriented services were not properly conceptualised and systematically implemented. They similarly noted the gap between rhetoric and on-the-ground support for consumer participation in mental health policy and services, stating, “Support for consumer advocacy, training, peer
support and consumer-run services is yet to translate into the resources and capacity building needed to assist consumers in these roles” (Senate Standing Committee on Community Affairs, 2008, p. xi).

As is shown later in this chapter, the approach to service-user participation described in federal policy aligned closely with the aspirations and values of service users, recognising, if nothing else, that the government had an awareness of what was important to service users. It was perhaps indicative of the influence which the mental health consumer movement had been able to exert on policy making that concepts such as consumer involvement, recovery, consumer choice, and service integration were prioritised approaches within the mental health agenda.

In relation to the mechanisms of consumer advocacy, the First National Mental Health Plan decreed that consumer advisory groups should be established at federal and state levels to ensure consumer input to policy making (Australian Government, 1992). At a national level, in 2010 Department of Health and Ageing commissioned a scoping study into the establishment of an independent consumer body to represent the voice of mental health consumers, in light of the fact that the Australian Mental Consumer Network had closed in 2008. The new body was to play a central role in informing the work of the first National Mental Health Commission, intended for establishment in 2012. The scoping study, developed after a series of national consultations with service users, recommended the establishment of a peak body, the purpose of which would be “to bring together a diversity of mental health consumers and mental health consumer organisations and groups enabling them to work collaboratively towards achieving a shared national vision leading to improved quality of life, social justice and inclusion” (Craze Lateral Solutions, 2010, p. 16). In 2011 Minister for Mental Health and Ageing, Mark Butler, indicated support and in-principle support for most of the
recommendations arising from the scoping report, noting the importance of the new organisation being “consumer driven” (2011, p. 2). However the Minister had, despite recommendations put forward by the scoping study for an initial consultancy group to guide the establishment phase and for it to be established as a stand-alone legal entity, opted for a model to be auspiced by the government for the initial 18 months, perhaps contradicting the emphasis on independence intended by the scoping study.

**New South Wales policy agenda**

In September 2010 the New South Wales Labor Government (2010) announced that 18 Local Health Districts would replace the former model of eight Area Health Services. The Local Health Districts had a greater emphasis on localised decision making and were administered by a Chief Executive and local Governing Council. During 2011 a Liberal government was elected into state office. These restructures meant that policies and frameworks were in a state of limbo or flux during the period of this study, impacting significantly on the policies’ relevance and currency. While much of mental health policy was within the domain of health agencies, the complex and important responsibilities for servicing mental health service users was seen to require specific strategic interagency collaboration across agencies such as health, justice, community services, education and also non-government sector (New South Wales Government, 2005).

One important initiative being driven by the new Liberal government was the establishment of a New South Wales Mental Health Commission, in line with the establishment of a planned national Mental Health Commission. Interestingly the government had introduced new legislation decreeing that the either the commissioner or deputy commissioner of the new body must have “personal, lived experience of
mental illness” (Corderoy, 2011, para. 3). This was considered a landmark move and indicative of the way in which the expertise derived from personal experience was being valued in the mental health sector.

While there were a number of important documents constituting the New South Wales policy framework on mental health, *New South Wales: A New Direction for Mental Health* was the overarching one, outlining policy priorities and key strategies, although this policy document was effective from 2006 to 2011 and so was nearing the end of its relevance at the time of this study (New South Wales Health, 2006). The state plan predominantly described the funding investment to be made in the four key areas of:

- promotion, prevention, and early intervention
- improving and integrating the care system
- participation in the community and employment, including accommodation, and
- workforce development.

The plan did not use the language of EBP or participation nearly to the extent of the federal policy documents. It described increased levels of investment in particular research programs, but did not specify the ways in which such research would translate into practice. The investment in participation strategies focused on accommodation options, such as the Housing Accommodation and Support Initiative (HASI), investment in training and employment programs, and increased support to the community sector to provide leisure and recreation activities. It is interesting to note the way in which the language of EBP and social inclusion emerged more strongly in the state policy documents produced from 2007 onwards. The state mental health plan was published in 2006, prior to the election of the Labor government at a federal level in
2007, which was the point at which the language of social inclusion became dominant. The New South Wales mental health plan featured one reference to “evidence based treatment” (2006, p. 9), and the overall state health plan, which was published a year later in 2007, featured two references (New South Wales Health, 2007b, p. 13, p. 27).

There were a number of state policies guiding the appropriateness and effectiveness of mental health services for specific groups of the population. These offered insights into the conceptualisation of EBP and participation in New South Wales mental health policy. For example, the Aboriginal Mental Health and Well Being Policy iterated the importance of developing strategies to “incorporate cultural/community values with evidence based practice” (New South Wales Health, 2007a, p. 25). Were EBP to be conceptualised in accordance with its original definition, such consideration of the evidence in accordance with cultural values would have been intrinsic to the process of EBP (Sackett et al., 1996). This policy also noted the importance of consumer representation on mental health working groups and sought to encourage consumer participation in regional area mental health services.

The Multicultural Mental Health Policy was developed in 2008, when the concept of EBP was gaining prevalence in Australian policy making. It featured a significant focus on EBP, and is interesting for the way in which it actually illustrated the challenges and opportunities for EBP, providing some indication of what was meant when policy makers within the mental health sector used this terminology. According to this policy, the establishment of mental health services to effectively meet the needs of culturally and linguistically diverse populations had been hampered by a lack of research into what works for these populations and by research methods which failed to be inclusive or representative of people for whom English was a second language. In addition to this gap in the evidence base, it was noted:
Often, evidence based practice has been established through the funding of pilot programs. To date, many pilot projects have been evaluated in an adhoc manner, rather than using empirically sound methodologies. This has resulted in difficulties in validating best practice and also risks duplication of resources and funds over time. An empirical approach will ensure valid data is collected, analysed and published in appropriate journals. It will also attract experienced researchers, expanding the current body of knowledge. Success requires strong and substantive links with relevant research institutions and universities (New South Wales Health, 2008, p. 14).

The conceptualisation of evidence as “findings derived from evaluation”, often evaluation of pilot programs, compromised the quality of the evidence. The structure of funding systems further compromised the translation of rigorous research into meaningful practice. Also, improved partnerships between government agencies and research institutions were seen as intrinsic to the implementation of EBP. Enhanced participation of culturally and linguistically diverse mental health consumers and their carers and families was also a priority in the plan. It was noted that all Area Health Services (now Local Health Districts) should have mechanisms to support such participation and should provide understandable, useful information about access to services and service-user rights.

The New South Wales Charter for Mental Health Care in New South Wales was also important in asserting the overarching principles and values to shape the provision of mental health services in New South Wales (New South Wales Health, 2000). The 15 principles focused on respecting consumers of mental health services, reducing stigma and discrimination, and ensuring human rights were met. Principle five aimed to
“Encourage true consumer involvement at all levels of service delivery and policy development” (New South Wales Health, 2000, p. 1). The use of the term ‘true consumer involvement’ implied an awareness of the tendency towards tokenistic modes of participation and recognition of the unacceptability of such approaches to participation. The charter was a one-page document summarising key principles so there was no expansion upon what was meant by the notion of ‘true consumer involvement’.

The New South Wales Consumer Advisory Group (CAG) was a primary mechanism by which New South Wales Health sought to gain the input of consumers at a policy level and New South Wales CAG was funded by the Mental Health and Drug and Alcohol Office (MHDAO) (New South Wales Consumer Advisory Group - Mental Health Inc, 2008). The Mental Health Consumer Perception and Experience of Services (MH-CoPES) project exemplified the relationship between formal consumer participation mechanisms and government in New South Wales. New South Wales Health funded New South Wales CAG to manage and deliver the MH-CoPES project, which involved the development, trialling, and roll-out of a questionnaire to be completed by consumers of Area Mental Health Services, the results of which fed into a six-month continuous evaluation and improvement cycle. New South Wales CAG noted:

… the involvement of consumers in each step, was a key facilitator of the success of MH-CoPES, and a catalyst for cultural change. The ongoing positive interaction between staff and consumers through a legitimised Framework facilitated a change in attitudes towards each other, and a reduction in stigma towards consumers (Doyle, Coleman, Oakley, & Malins, 2009, p. 7).
The involvement of consumers in shaping the evaluation tool and delivering the MH-CoPES project was seen as crucial, in addition to the actual value of a mechanism for consumers to provide feedback about their service experience at an individual level. New South Wales Health (2007b) noted, in seeking to achieve the goal of increased customer satisfaction with its health services, the MH-CoPES tool would be specifically used to measure and report on the satisfaction of mental health clients.

**Local and regional policy agenda**

Due to the reform of service delivery agencies and the development of regional Local Health Districts, the strategic planning processes of a number of the mental health policy agencies at a regional level were difficult to track during this period. Strategic planning and policy documents pertaining to mental health and participation were inconsistent across districts, even more so as the newly formed districts resulted in the amalgamation and restructure of former health areas. Specific responsibilities for strategic planning for mental health service provision in the government sector lay largely with health agencies.

Hunter New England Health’s (2006) mental health program was operating under the *2006 to 2010 Mental Health Service Plan*, which despite being outdated, was useful in identifying the ways in which the notions of EBP and participation played out at a regional policy level. There were frequent references to the implementation of interventions which were “evidence-based”, with the specific objective of achieving, “Safe and evidence-based healthcare focused towards recovery” (Hunter New England Health, 2006, p. 11) This was indicative of the way in which concepts of EBP and recovery were used in tandem. Communities, consumers, carers, and families were one of four focus areas within the plan, with the participation of consumers central to this
focus. Strategies included consumer participation in workgroups, gaining consumer feedback, consumer input to clinical decisions, and appropriate support and resourcing for consumer consultant roles.

Northern Sydney Local Health District’s (formerly Northern Sydney Central Coast Health) mental health strategic plan similarly emphasised a consistently evidence-based approach, but this was very much in relation to clinical service delivery and equated EBP with the development of clinical guidelines (ie. an emphasis on practices rather than process). There was little indication of how the evidence-based focus would be achieved. As with most other local health service providers the strategic plan highlighted the importance of partnerships with consumers and carers, indicating that consumers would have representation on all service redevelopment and planning forums and that strategies would be developed to increase consumer participation in the workforce. At an individual level they sought to increase, “Involvement of consumers and carers in care planning and evaluation of individual goals” (Northern Sydney Central Coast Health, 2006, p. 4), which was also one of the agency’s key performance indicators. The health service coordinated an area mental health consumer network which met monthly to act as a steering committee.

Service user Sarah highlighted the gap between the intentions and rhetoric of policy and the realities of being the end service user:

You know, we have all these national standards for mental health and, you know, it's, it's like they've gone out and left us all behind and have got all this, you know, nice, you know, the nice words are there, the nice policies are there, but they've left everyone behind.

The federal, state, and regional policy documents indicated a strong focus on
diverse interventions based on rigorous evidence, with consideration given to the complex and unique needs of individuals, founded on principles of recovery and client-centred approaches. However, as is shown in the analysis of interviews and focus groups with mental health service users and interviews with service providers, the experience of using mental health services belied such policy intentions and was a confusing, frightening, and vulnerable process, whereby the impetus was on consumers to become informed, confident, and well enough to advocate for themselves to get what they wanted from the services system.

**Overview of participation mechanisms**

People with experience of mental illness were, historically, at the forefront of the service-user participation movement internationally. In Australia, the mental health participation movement evolved into structured and often systematic mechanisms for service-user input intended to feed into policy agendas regarding consumer participation and client-driven strategies. The New South Wales CAG evolved from the government’s strategy to engage the participation of mental health service users in the development of the *National Mental Health Plan* (Australian Government, 1992; New South Wales Consumer Advisory Group - Mental Health Inc, 2008). At the time of the study, it was the primary mechanism by which consumers fed into the policy making process at the state level. However, there was a plethora of mental health consumer participation groups and activities within Australia. They varied from grassroots, unfunded voluntary activities to incorporated, funded professional advocacy organisations and even consumer organisations delivering services. The prominence of peer-support and self-help strategies within the mental health sector meant some
participants within these types of peer groups also forged roles as service-user representatives and advocates in driving mental health program and policy reform.

The Schizophrenia Fellowship is a community organisation supporting mental health consumers and their carers by delivering programs and providing individual and policy level advocacy (Schizophrenia Fellowship of New South Wales Inc, 2008). Peer support is a component of many of its interventions. Despite its status as an independent community organisation, a significant proportion of funding is received from federal and state government agencies. GROW brings together small groups of people suffering mental distress and employs a 12 step recovery model to work towards mental health (GROW, 2010). CAN (Mental Health) Inc. is an example of an independent consumer-run organisation that offers phone line support, peer support programs and recovery centre activities to those with mental illness (CAN Mental Health, 2007). There is also a range of online forums through which mental health consumers provide peer support, share information (including information on latest research and evidence and opportunities to participate in research and clinical trials) and strategise regarding advocacy. These include consumer run forums such as depressionNet and government funded, but community sector managed sites such as Headspace and beyondblue (beyondblue, 2011; dNET - People Like Us, 2011; Headspace, 2011). While not an exhaustive list of the participation agencies and mechanisms for mental health service users in Australia and New South Wales, these examples demonstrated the well-established nature of service-user participation in this sector. It should be noted, in describing the quantity of participation mechanisms, there was no attempt to consider the effectiveness or quality of those participation structures and mechanisms.
Service-user perspectives on participation

The range of participation activities described by the mental health service-user interviewees was diverse, representing the plethora of participation mechanisms in operation in Australia. Participants were recruited through email bulletins and newsletters published by mental health consumer organisations, but they were not necessarily members or active participants in either of these organisations or, alternatively, they had participated actively in these and numerous other organisations. Most of the service users had participated in multiple roles as consumer representatives or advocates. Many had been in salaried roles:

- Two had been employed as consumer consultants with their local public health service.
- Four had been paid salaries from community-based organisations where they were employed in designated consumer roles (usually part-time or casual), such as working as a consumer consultant to provide advice to clients of the community mental health agency, mediating between workers and clients of the agency, and advocating on the behalf of clients of particular mental health services.
- Two had been employed in research and policy-related roles where they facilitated consultations with consumers, wrote and contributed to reports and other documents, conducted literature reviews, and designed research tools such as surveys and questionnaires.
- One had been employed as a project worker, leading a small team of staff and volunteers to implement a program to support carers of people with mental illness.
- One had worked as a professional in the mental health sector, but had not identified her status as a mental health consumer to her employer and was not in a consumer designated role.

- Six had participated on at least one, but more often multiple, committees as mental health consumer representatives. These were generally unpaid positions, or came with a small honorarium to cover associated expenses. The types of committees included steering committees for specific mental health projects, networks of local mental health service providers, clinical networks such as hospital staff or general practitioners, and mental health research steering committees.

- One service user ran a local peer-supported recovery group as a volunteer.

  Elizabeth and Amanda had been reluctant to participate in structured consumer activities or to identify in public advocacy type roles. However, Elizabeth completed surveys occasionally when she received them in the mail with mental health related newsletters. Amanda had written letters to politicians and key policy makers as part of targeted campaigns conducted by one community organisation, advocating on issues such as access to certain medications. One interviewee, Brian, did not participate in any activities and only received a regular newsletter from one mental health organisation, to which he had subscribed many years ago. He stated, because of his physical health problems, “it'd be very difficult for me to participate in much at all” and also noted he wasn’t ideologically motivated to participate because society already viewed him as a “bludger” and he, therefore, didn’t feel comfortable advocating for anything more than he was already receiving. In general, however, the service users interviewed were active advocates and had, in some capacity, undertaken tasks to improve the conditions for mentally ill people and to address stigma and discrimination around mental illness.
The organisations and agencies in which the service providers worked had attempted and adopted a range of service-user participation strategies. Some had dedicated consumer positions on their management committees or boards. Three of the organisations represented by service provider interviewees had employed consumers, in either one-off or ongoing capacities, to consult on project design, support the delivery of projects, conduct research such as surveys, and assist with administration and other operational aspects. Two of these organisations had not sustained the employment of consumers because they had decided the model was ineffective. One service provider noted the organisation had changed its philosophy to ensure consumer advocacy was intrinsic to all staff and not just the perceived responsibility of one consumer representative. Another noted that paid roles were difficult to sustain because there were limited resources and funds and because it was difficult for consumers to commit to ongoing roles while managing their mental health issues. All services had mechanisms for engaging clients in the decision-making processes of their organisations in unpaid capacities. This included consulting consumers about policies, getting them together for workshops or informal functions to give feedback about programs, service quality, and organisational policies, encouraging clients to give feedback and be involved in decision making at individual levels of interaction, and having formal complaint or feedback processes for clients. While participation of service users was seen as an effective and ethical way of practising, service provider Fiona noted significant pressure for mental health services to have service-user participation strategies in place deriving from social and community expectations.

Despite the numerous examples of service-user participation strategies cited throughout the interviews, there was an underlying tension in the modes and mechanisms for service-user participation in the mental health sector; between a
movement premised on distrust and anger towards the system and the need to work with, and often as part of, that system to enact change. Cruikshank (1999) had asserted that many participation strategies were coercive and manipulative mechanisms, which sought to achieve compliance rather than radical systematic change, and which did not challenge power imbalances between authoritarians and marginalised or vulnerable people. This assertion played out strongly in the ways the service users described their passion and drive to elicit change, while facing innumerable conflicts and challenges as participants in these processes.

**Motivations to participate**

In general, service users believed themselves capable of valuable contributions to society and of meaningful participation in society that may have been only temporarily compromised during times of extreme illness, such as the experience of major psychosis. That society, and the human and health services system did not always afford equal opportunities for participation was a motivating factor for many in the experience of being a consumer advocate and representative. Tara stated:

> I know the things that can change just from my life and my experience and I know what's happening and it's just ... I have empathy with the people who use the system and who don't know what I know. And I know that what I have learnt is useful and I want to share that.

Sarah and Martha wanted to be able to support other consumers to be able to make decisions for themselves and to be active participants in their treatment. Sarah also noted clients, particularly those who were new to the system, lacked a voice and the skills, confidence, and ability to speak up for themselves, especially within hospital
settings. Tracey similarly saw her paid and voluntary roles as a means to inform people, help them navigate the system, empower them, and stop them feeling alone.

Greta and Martha wanted to be role models of how recovery from mental illness could be achieved, despite the tendency for mentally ill people to be treated as incapable and dysfunctional. Greta aimed to “make people understand what happens to people in the system”.

While Elizabeth was reluctant to become a consumer representative herself, she described her experiences of hospitalisation and treatment in the mental health sector as frightening and isolating and thought consumers could help each other to have a voice in this difficult system. The experience of being a user of mental health services, trying to identify and access the most appropriate services, maintaining independence and confidence while a client of those services, and understanding the illness and the options for treatment and recovery were seen as challenging and overwhelming tasks. The service users felt the frightening nature of serious mental illness was often exacerbated by attitudes, a lack of compassion, incompetence, and exhaustion among some professionals within the health and human services sectors and a lack of resources available to support clients and their recovery. The system had failed and so service users saw they needed to step in to address this failure, using the knowledge and skills they had built through their own experiences.

**Participation as a means of dealing with stigma**

The challenges of participation were largely described in terms of identity, and the language of ‘stigma and discrimination’ was used to talk about the marginalisation and misrepresentation of mentally ill people. Most participants described a period in their
lives where they attempted to hide their mental illness, due to feelings of shame and fear of discrimination.

Service user Sarah described how she didn’t want the “label” or the “stigma” of mental illness attached to her. For her, engaging in the consumer-participation movement as a professional consumer consultant was a significant step in conquering the sense of shame she felt about her illness.

Service user Tracey questioned why there was so much stigma, shame, and secrecy around seeking services to address mental illness, whereas for other illnesses, such as diabetes, it was a straightforward process to seek support and treatment. The drive to reduce stigma and improve the status of people living with mental illness was the compelling force in Claire’s decision to become an active consumer representative and advocate. She, noted: “they've [the general public] still got that image in their mind of mental illness being a terminal condition that you get shut away in the house on the hill for”. A number of interviewees mentioned the way in which some prominent Australians, including actors and politicians, had spoken publicly about their own mental illness and challenged stereotypes. They saw this as a positive step towards breaking down stigma.

Amanda and Luke believed the ability to continue meaningful, stable employment was an important aspect of managing their illness and believed it was important that false assumptions and stigma regarding mentally ill peoples’ capacities to work needed to be broken down to afford more people with mental illness the opportunity to work and participate in this central component of society.

Tara and Elizabeth felt their decision to talk openly about their mental illness limited or ended employment options and resulted in a loss of income. Tara knew of many people, particularly people working in the mental health sector, who were “in the
“closet” about their mental illness because they were fearful about the workplace discrimination they would encounter.

While becoming a consumer advocate was a mechanism to fight stigma, paradoxically, participating in groups under the label of ‘mental health consumers’ was also a means of reinforcing stigma and diminishing individual’s uniqueness, humanness, and complexity. One of the key challenges to engagement in the service-user participation movement was the desire for balance and ensuring that mental illness did not become the definitive feature of an individual’s life. Fraser (2000) cautioned against the potential for an identity-focused model of recognition to lead to the reification of identity, noting it tends to stress “the need to elaborate and display an authentic, self-affirming and self-generated collective identity, it puts moral pressure on individual members to conform to a given group culture” (p. 112). She saw the propensity for stereotypes and labelling to become reinforced, whereby a heterogeneous group of people who happened to share one common factor became grouped together and marginalised. Many of the service users were similarly cautious of the capacity for participation strategies to reify identity.

In describing her consultation work with other mental health service users, Greta said she had regularly heard people complain about feeling dehumanised by being treated as a “bunch of symptoms”. For her, the unease at being grouped with other service users was highly problematic, because she had opted for non-mainstream recovery options and was staunch in her independence, noting, “that's why I walked away from, from those sort of, um, peer groups because I'm a different, I'm doing it in a different way”.

Similarly, Sarah had moved away from participating in peer-support groups and structured consumer participation forums because she felt people could stagnate or
become trapped in their own illness. While she noted the support of fellow consumers had been useful at the early stages of her mental illness, she felt it was important to move forward and to ensure her identity was not caught up in the label of “mental health consumer”.

The potential for the service-user movement to affect significant change was limited, according to Claire, because “whilst it can be a very, you know, pervasive part of your life, it is just one part of your life. Most people have lots of other facets to them as a person than their illness”. She saw that people needed to focus on other aspects of their lives rather than be involved full time in advocacy and service-user participation activity.

Brian was highly sceptical about formal service-user participation mechanisms and favoured an individualistic approach whereby he did not consider advocacy and participation to be worthwhile activities because any change was unlikely to occur within his lifetime. Wendy had avoided identifying as a mental health consumer, particularly within her professional practice, and saw that focussing on talking about her own issues could be distracting when working as a professional in therapeutic interventions. Instead, she used the sense of empathy and insight gained from her own experiences of mental illness as unspoken tools to support the way she engaged with clients.

Elizabeth was, by her own admission, a quiet, shy person who was not comfortable in public roles or in most of the group activities associated with service-user participation. However, she practised her own type of advocacy within her interpersonal relationships, by demonstrating to the people she met that people with schizophrenia were not frightening, aggressive or strange, thereby challenging stigma.
Challenges of participation

The historical mistreatment of people with mental illness and a sense of anger towards the system that doled out poor treatment and stigmatised the mentally ill led to a consumer movement premised on amending and ending such abuse. Therefore, the participation of service users within the system became important, as though from within they could stop mistreatment from happening. The paradox for the majority of the mental health consumers interviewed was the notion that to change the system that they felt had been the source of much hurt and even trauma, they needed to work with, and often within, that very system and sometimes in bounded roles that led them to feel further excluded or marginalised. This was at the heart of the frustrations that interviewees had experienced in their roles as consumer representatives and advocates. Most service users were critical of forums in which their participation had been tokenistic.

Tara and Claire described experiences as consumer representatives on committees where they had not been listened to and where their ideas and feedback had been ignored or undermined. They made clear that having a seat at the table in decision making and policy-making fora was not sufficient to constitute participation. The examples they cited where their participation had been effective, and where they had felt listened to, were those where their involvement was long term and their roles were clear.

For Greta, the reluctance on the part of government and non-government organisations to pay consumers for their input or to provide them with adequate resources such as computers, internet access, and telephones, was an indication of the low value placed on consumer participation and the lack of understanding regarding the challenges to participation. She found her desire to be paid for her time and expertise
had been a point of contention in many activities, where other consumers did not consider payment necessary or appropriate, or where the workers involved had limited funds or willingness to provide payment. This was a major barrier to participation where costs related to travel for meetings, internet access, and telephone usage were incurred. Further, she and other interviewees noted the economic costs of mental illness which were exacerbated because full-time employment had often not been possible. Poverty meant payment for preferred treatment options was difficult, relationships with conventional support providers such as spouses and other family had broken down, and many were living on disability pensions.

The frustration with lack of payment for services rendered as a consumer consultant or consumer representative was indicative of the economic cost of participation and of a desire to be treated on par with professional counterparts. It represented a conflict between enthusiasm for the opportunity to participate, but anger with the manifestation of that participation and recognition that many of the opportunities were not achieving real changes in power. Greta said:

And I felt privileged in a way that I was, yeah, and grateful that your voice is heard ... then I looked around and, that psychiatric nurse's probably getting, what, $50 an hour or something, on work time, you know car and everything.

In response to the perception that their participation was tokenistic or poorly-valued, service users strove to achieve legitimacy and achieve a degree of equality with sector professionals.

**Professionalisation of the consumer role**

The professionalisation of consumer roles was indicative of the way in which service-user participation sought legitimacy and power. Community-based mental health
organisations were increasingly engaging skilled consumers as paid employees where possible, in recognition of the importance and value of their work. Service users who had undertaken employment as consumer representatives felt this professionalisation of their roles was important, and it allowed them to provide support to their peers in a more informed and effective way. For Tracey, this professionalisation was:

… really crucial. I mean the great thing for me is that I can walk into any ward at any time and as a team member I can go and look at any of the files. I can sit in on any of the staff handover meetings or the case-planning meetings, I can question.

Other service users had found it challenging to balance their dual position as consumer and professional, noting they had often been questioned about their qualifications for the role and feeling very mindful of the workplace hierarchy, with consumer workers at the bottom. It is worth noting, during the period of this study, New South Wales CAG was undertaking a project specifically to examine the challenges and benefits of professionalisation and to develop standardised practices and pay rates for this type of employment (New South Wales Consumer Advisory Group - Mental Health Inc, 2011).

Service users Greta, Tara, Claire, Wendy, and Martha had undertaken formal study in social science or community service disciplines, including degree-level qualifications. Tara explained:

I remember being, trying to communicate that I wasn't happy with what they were saying … and saying well ‘stuff you, you don't know what you're talking about, you will not listen to us, you don't want to hear us, so I'm going to go and get a degree and get your qualifications so that you will have to listen to me'.
Becoming formally educated in the sector in which they were service users was a means of understanding the conditions and issues affecting them, arming themselves with knowledge and skills so they could more effectively perform their function as a consumer representative and achieving legitimacy and equality. Tracey and Amanda were trained professionally in health and welfare related disciplines prior to their diagnoses of mental illness and had used the skills and knowledge from their formal training within their participation activities. While the notion of service-user expertise is examined later in this chapter, it is worth noting the way in which service users sought to supplement the skills and knowledge gained through their lived experience with academic training from formal and conventional institutions. This also reflects the expectations upon service-user representatives to fit in with professional forums, where the demands on time and intellect could be substantial.

The demands on service users to participate in large numbers of forums, especially those where they were a lone service user working with groups of professionals, were enormous and often seen as disincentives to participation, or factors which limited the ability of people to participate. In many instances, it was the service user who was required to quickly acquire new skills and knowledge and extend themselves beyond their comfort zone in order to participate in structured, professional forums, such as committee meetings. The amounts of reading required were often arduous. There was little evidence that the professional sector had adjusted their structures to create more equal involvement of service users, other than to allow the service users into their existing fora. Most of the compromise was made on the part of the service users who were often out of pocket, busy, and overwhelmed. The experiences of the respondents in this study supported concerns of Hodge (2005) and Barnes (2009) that the personal and passionate nature of service-user input had been
discredited, and participation was premised on service users being able to restrain and contain their emotions.

Claire suggested that to participate in the range of committees and consultancy activities with which she had been involved, “... it’s not enough just to be a consumer. You also have to be like an intelligent, informed, articulate consumer”. Martha, who had participated in, and even chaired, various local committees of mental health professionals considered that the potential for consumers to be involved in policy work was limited because “I don't think a lot of people with mental health issues would be able to go through all that gobble-de-gargoyle, to you know, know about the policy”.

The ways in which certain modes of participation relied on the internet, such as online surveying and email newsletters, were also seen as exclusionary. For many, the costs associated with computers and internet access were prohibitive and for others the technical skills were challenging. Service provider Cara was mindful of technology’s capacity to provide new opportunities for participation by engaging with people who might otherwise be isolated, but to also create barriers to participation for those without the skills or means of accessing internet.

**An optimistic outlook**

The preceding analysis has shown the significant challenges to redressing the disparities in participation for mentally ill people. However, overall, the service users and service providers in this study expressed hope and optimism about their capacity to overcome subordination and achieve greater equity. Most were passionate in their commitment to change and were positive about their roles. The service users believed their representation had led to a number of positive consequences: They had been able to give fellow consumers information about their rights and options for treatment and support...
they otherwise would not have received. They had allowed clients and patients in service settings to open up and express concerns and fears they would not otherwise have expressed to usual staff.

As a consumer consultant providing her perspective on important policy issues, Tracey felt a trusted and valued member of the mental health team. Service providers Cara and Jacki saw clear evidence of service-user involvement resulting in better quality projects, more in line with what consumers wanted, within their organisations. They observed higher response rates to surveys where consumers were involved in their design. Service policies and guidelines were better understood and adhered to when consumers had had input into their development.

Some of the most interesting insights came from those who sought to subvert disparities in formal mechanisms of participation. Though interviewees talked about the transformative effect of their participation, most of their interactions were at an individual level. For example, Elizabeth saw herself as an advocate because, in her interpersonal interactions, she challenged people’s prejudices and stereotypes around schizophrenia. Wendy had established herself as a worker in the mental health sector on her professional and academic merits, without identifying as a consumer, but had used the empathy and insights from her own experiences to enhance the way she worked with individual clients.

Almost all interviewees described a feeling of self-worth, or improved self-esteem arising from the process of service-user participation frequently using phrases such as “having a voice”, “giving a voice to”, “empowerment”, and “connecting” when discussing the participation process. They saw participation as an intrinsic part of recovery, believing service users needed to increase their level of input and control in individual-level decision making and, for some, at a program and policy level also.
Service-user perspectives on EBP, evidence, and service-user expertise

Importance of lived experience

As with users of homelessness related services, those within the mental health case study saw their unique knowledge gleaned from living the experience of mental illness as a source of special and valuable expertise. Most saw their sharing of their knowledge and insights with fellow consumers as an important tool in recovery. For example, Tara said “most consumers will tell you ‘well actually the best thing about being in hospital was talking to the other consumers on the verandah and that's how I got well’ ”. For Sarah and Elizabeth, in conducting their own investigations into schizophrenia in search of information about their illnesses, they had been heavily influenced by accounts of the experiences of other service users. Sarah described how, when she looked for books or articles on the internet, she was drawn to those written by people who had experienced mental illness. She looked for those where she felt “well that's similar to what I'm experiencing, so … there must be something in that”. While Elizabeth had shied away from peer support forums, because she was not comfortable spending significant amounts of time with other mentally ill people, she noted she nevertheless felt an “affinity” with people who had experienced mental illness and shared their knowledge. This encouraged fellow sufferers to speak freely and develop an understanding of one another. In her work as a consumer consultant, Tracey would tell clients immediately she was a fellow consumer, because this was an effective way of breaking down barriers and establishing a “connection”. She said that this came about because consumers felt a fellow consumer would understand them and their experiences better than other staff. Despite the fact that service-user representatives and paid consumer workers may have
experienced different types of mental illness or had different experiences of the system than some of their peers, their insight and capacity to engage with the fellow service users was considered superior.

Greta saw “lived experience” as a highly valuable but contentious source of expertise to be treated with great care. A significant part of her work as a consumer advocate was to gain recognition for the importance of this lived experience in treatment and support decisions, but also important was training, education, and skill development. She cited examples where consumers had been placed on committees to share their experience-based knowledge but where, because they were poorly trained and lacked support in their role, they had broken down and appeared fragile, reinforcing stereotypes of the helplessness of people with mental illness. Greta was mindful of the way in which people’s stories could be taken over by mental health workers and researchers and retold and manipulated in contexts where individuals lost ‘power’ over their stories. To retain power, she was very selective about sharing her story with professionals or in public fora. In contrast, other interviewees made their stories publicly available, seeing them as a source of knowledge and shared expertise. One service user had written and self-published books about mental illness, which told of the personal journey through mental illness and the strategies that had worked in dealing with it. A number of participants had spoken publicly about their experience of mental illness at conferences, community events, and professional networking meetings. For these service users, sharing their stories and suggestions enabled them to support other consumers in making informed, insightful decisions, enhance workers’ understandings of mental illness, build better strategies for working with people with mental illness, and break down public stigma. These approaches to the dissemination of service-user expertise highlighted its personal nature and the complexity involved in working with a
type of knowledge stemming from lived experience.

For Amanda, it was crucial for service users’ insights to contribute to the development of treatments and support mechanisms, especially regarding the side effects of medication. If clinicians did not understand the effects of medication they could not meet the patient’s needs or ensure their compliance with treatment regimes. She knew of a number of people who had not complied with medicine regimes due to the significant weight gain they experienced as a side effect, noting that until the patient’s expertise in the experience of that side effect was acknowledged, the therapy was unlikely to work. Claire observed how “the insider's view of how it feels” sometimes challenged professional egos and practice wisdom. Reflecting her consumer perspective, she believed “no-one can ever understand, really, how it feels, unless they've gone through that experience”.

Service providers were in agreement on service-users being experts on their own illness, seeing this as a fundamental principle of the client-centred approach (proposed by the Fourth National Mental Health Plan). In her consumer-advocacy work, Cara believed it was important to treat consumer ideas and opinion as the “primary source of evidence” supported by knowledge from journals and more conventional forms of literature. Jacki observed this approach accorded with the principles of recovery where service-user expertise was a valid source of evidence.

**Confusion regarding the meaning of EBP**

Service-user expertise seemed problematic when it came to understanding and clarifying the nature and value of evidence in practice and policy making. While the service providers and service users interviewed saw lived experience as crucial in informing practice, most were not sure how it could or should fit with EBP. Greta
encapsulated the common dilemma:

I think [it’s] … supposedly evidence-based that cognitive behaviour therapy has the most impact for people for change. And when I see that I say ‘not really, not for me’ you know. So, and I know that's evidence-based and I know it's probably anecdotal what's happened to me, but those stories are important as well aren't they? That's how I feel.

Understandings and experiences of EBP revealed it was an oft-cited but rarely understood concept. Two of the eleven service users interviewed had sophisticated understandings of EBP aligning with definitions from the literature. Both were university educated. Six were familiar with the concept of EBP, but offered a description outside conventional models of EBP or were not confident in describing what it meant. Three were unfamiliar with the term. Of the six service providers interviewed, three were knowledgeable about EBP, two had some knowledge, and one was not able to offer a definition.

The extent of service users’ experience of EBP in their interactions with services varied significantly and depended on their understandings and perceptions of EBP. For example, Sarah saw EBP as an individual approach to treatment where the client’s ideas and values were taken into consideration. She believed the recovery program in which she had participated was evidence-based because it had been consultative and a range of options during the planning process had been discussed. On the other hand, Tara said most services she had encountered were not evidence-based because they did not evaluate their programs or apply methods such as critical incident techniques.

Most of the service users and service providers interviewed understood EBP as practices with positive effects because they were research based, rather than part of a
process as described in early models promoted by its most ardent advocates (Gambrill, 2010; Sackett, et al., 1996). Cognitive behaviour therapy was the most prominent example of an evidence-based practice, cited by service users Greta, Tara, and Amanda and service provider Dawn. The notion of EBP as research-proven practices, rather than an intervention process, was fundamental to their concerns and reluctance to embrace EBP. For service user Greta and service provider Dawn, it had been a struggle to gain acceptance for, and access to, therapies other than cognitive behaviour therapy because of the presumption that cognitive behaviour therapy “works”. Greta said:

I'm the one that's recovered in a completely different model because of who I am I suppose and, and people coming into my life, the opportunity. But it's too bad, it's like I suppose alcoholics and they say you can't touch a drink. There are some people that can drink a bit and you know, and it's too bad if we're all under that one size fits all.

Gambrill (2010) argued EBP had lost the important focus on individual context because it had been misconstrued as proven practices rather than as a process involving client values and professional wisdom as suggested by its early developers. This was borne out by service users and service providers who saw EBP as a limiting and constrictive set of treatments because it failed to consider their unique individual circumstances. Because of this misinterpretation, EBP was seen by some as incompatible with the principles of recovery.

Each of the service providers interviewed struggled to reconcile their notion of EBP with the high importance they placed on client-centred, personalised, recovery-oriented outcomes. For Cara, quantitative evidence was considered “rigorous” but this was highly problematic to those researching the types of personal outcomes promoted
through recovery models. Likewise, Jacki and Brenda associated evidence with data and statistics, and resisted models of practice with undue emphasis on this type of “outcome”. Fiona had a strong understanding of EBP as process-oriented and high regard for transferrable and contextually relevant evidence. However, she also believed practice wisdom was vital and research-generated evidence needed to be considered carefully alongside practice wisdom, in keeping with Sackett et al.’s (1996) early definition of evidence-based medicine. Dawn was guarded about EBP because she saw it as overly prescriptive and not necessarily client-centred. However, Dawn described her preferred way of working as the type of process EBP advocates such as Gambrill (2006b, 2010) and Chalmers (2005) had promoted. She consulted closely with clients about their issues and their goals for recovery. She discussed the range of treatments, services, and resources in the community and gauged the appropriateness of these interventions for the individual client. She presented and discussed research and other types of information regarding available treatment options. When one intervention did not work, she repeated this process with the client ad infinitum.

Fiona warily noted the propensity for evidence to be manipulated or biased: a concern reflected by a number of service users who had experience of working with researchers or in environments where research had been seen as promoting, or demeaning, certain practices. Of concern was the potential for EBP, through tools such as the hierarchy of evidence, to favour medical models of mental health because the types of evidence favoured in the hierarchy were perceived to be more dominant in medical and pharmaceutical sciences and less likely to be able to be funded and sourced for alternative and emerging non-clinical interventions. For them, evidence was not neutral or objective.
Promise of EBP

Despite significant concerns expressed about EBP, largely founded on interviewees’ particular understandings, most agreed policies and program interventions should be based on evidence. Real excitement was conveyed about the potential for evidence to support the aspirations of some service users.

For example, service user Claire talked about research demonstrating the benefits and potential for the employment of people with mental illness, which broke down common myths and stereotypes about the nature and impacts of mental illness. She saw this type of research as directly impacting on the range of work opportunities now available to people with mental illness. Consequently, more employers were likely to take on staff with mental illness because there was evidence to support such practice. Similarly, service user Tracey believed research findings demonstrating the benefits of consumer participation and client involvement on mental health outcomes had been significant in fostering a more positive and genuine approach to service-user involvement in the organisation where she was employed. She was able to refer to studies that had influenced the organisation’s approach to consumer involvement. In this case, EBP enhanced the parity of participation by disproving the false assertions underpinning discriminatory practices.

Wendy believed it would be useful to her if practitioners were able to introduce discussions of the evidence supporting various treatment options into their interactions, but noted this would need to be done in a very careful way, where the information was presented in lay terms, and in context, rather than blanket statements about what works. For her, EBP could be an effective means of introducing new ideas and options for treatment into her therapeutic interactions. It was a way for clinicians to broach new strategies. As a service user who had also worked as a service provider and who had
studied in the social sciences, Wendy was able to reflect on the difference between practice and research, seeing them as separate and often conflicting or competing fields.

Tara was highly critical of the biased nature of evidence. However, for her, a broad and holistic model of EBP would be highly valuable to transparency, accountability, and enhanced choice in recovery: “Consumers shouldn't have to do their own research to find out if … [a treatment or program were] evidence based. They should not be lied to and they're being lied to, everywhere”. As such, EBP was seen to be a professional responsibility and a mechanism to ensure practitioners were accountable to clients.

Amanda saw EBP’s potential for change, noting “the only way things are going to change is because of the evidence that's been presented”. For her, EBP had been crucial in identifying harmful and ineffective practices and promoting improved interventions, such as Patrick McGorry’s work in establishing user-friendly drop-in centres for young people to access community-based mental health services instead of having to go to hospital emergency departments.

While uncertain about EBP and its potential, service users Elizabeth and Luke were adamant mental health services should be founded on evidence or reliable research. Their attitude reflected a general feeling among the interviewees regarding the value of sound, rigorous research and the responsibility for those in authority to look to evidence, regardless of whether they called it EBP or some other type of practice, and whether or not it incorporated other types of knowledge, such as professional wisdom or service-user expertise.
Participation and evidence in decision making

Efforts to retain decision-making power

Clearly, then, most interviewees believed evidence was important in decision making. Claire saw this as fundamental to accountable and effective practice, but indicated that many people early in treatment for mental illness did not feel “empowered” to ask questions about the evidence to support various treatments or about the range of evidence-supported options. This notion of empowered decision making was central for interviewees, who tended to describe a marked difference in their decision-making processes in the early stages of their mental illness or at periods of significant illness, such as psychosis, compared with their decision-making processes after years of experience in the system and after a degree of recovery. For Sarah, at times of crisis when she was experiencing severe episodes of schizophrenia-related psychosis, she needed to be able to rely on professionals to make good decisions for her, because of compromised decision-making capacity. She noted her perspective had been unpopular with some of the service users she had met in peer-support groups, describing arguments with fellow service users who advocated that choice should be provided about all aspects at all times. She said of informed decision making:

… when you're in the middle of a psychosis you can't. And you have to rely on the fact that those staff members are going to make good decisions for you because, either you're under the Mental Health Act, or you've been through the Tribunal. They say you're going to stay there another two weeks or fortnight or month, whatever ... Um, you have to do that and make, and believe that they've done their research. That they know what they're talking about and relying on them to make good decisions for you. Now it's another case. If I was to go back
into hospital now I would, if anything was something I didn't agree with, well I'd stand up for myself and say that.

For Sarah, trusting professionals to make good decisions meant trusting them to be kind, respectful and to be basing their practice on reliable research or evidence. Most participants said, when they were severely ill, they just needed to focus on getting better, and their capacity to engage in informed decision-making processes was necessarily limited. The collaborative model of evidence-informed decision making proposed by Gambrill (2006b) was neither experienced nor preferred during acute episodes of psychosis, such as those resulting in hospitalisation. However, this did not mean service users were not interested in participating in or retaining power over their decision-making processes. In response to the challenge of retaining their decision-making power while experiencing debilitating illness, Tara had developed an Advanced Plan, also known as a Management Plan or Ulysses Plan. Tara had collaborated with key service providers, when she was in good health and clear in her decision making, to document her preferred options for treatment and support when she was severely ill, such as during a relapse of psychosis. At these times, professionals took account of her preferred options in their decision-making processes. The plan had worked effectively for her, exemplified by an instance of relapse where she was able to avoid hospitalisation and stay at home to receive treatment which included medication and support from a network of service providers and friends. Tara reflected the perspective of a number of interviewees in describing the way in which she felt empowered and in control because she chose when and how her decision-making functions were handed over. She noted “there are times when you are incapable of coping and part of the choice might be to say, look I need someone else to manage my life for me right now.
And that's a choice too”.

Recognising there were times when service users might need to relinquish some control over decision making seemed to add value to the importance of the relationship with professionals. Trusting and respectful relationships with professionals were seen to be important at all times during interactions in the mental health sector, but the importance of this relationship seemed to be even greater at times of vulnerability or illness. In discussing the way in which they made their choices, all service users interviewed described at least one example of a positive relationship with a professional that was of vital importance in facilitating their decision making and, in most cases they considered this a transformative or critical intervention. Most service users also had examples of poor relationships with service providers where they had felt abused, neglected, disrespected, or patronised. For Elizabeth, it was simply important for staff to be “kind” and “nice”, because the experience of mental illness and the experience of accessing mental health services could be intimidating and frightening.

As suggested by Sarah’s earlier comments, once service users had achieved a state of better health, increased their knowledge about the treatment options available, become more experienced in navigating the system, and developed confidence, then they expected to be active partners in decision making. At this stage, they wanted their relationships with service providers to be more like collaborations or partnerships and less authoritarian. Reclaiming their power over decision making was fundamental to the process of recovery. All but one participant described their reluctance to make clear preferences for treatment or support programs in the early stages of their mental health issues, but once their health stabilised and they had gained experience in their use of mental health services, they became significantly more proactive in their decision making and able to make informed decisions about their treatment and support. These
findings corroborate earlier studies demonstrating disparities in individual capacities to participate, based on service users’ level of functioning at a given time and willingness to participate on the part of those wanting to move beyond their mental illness (Hickey & Kipping, 1998; Lammers & Happell, 2003; Tobin, et al., 2002).

The caveat was their belief that, in many instances, there was no choice to be made because there simply were no options available, a belief expressed by service users and service providers alike. Service user Tracey suggested clients generally needed to fit within existing services, which meant they made pragmatic choices to use services that were affordable, accessible, and had vacancies. The choice was even more limited in rural areas, where the numbers of services were small. Service user Claire noted the restrictions on choice due to the limited resourcing of the system, which had the flow on effect of service users needing to live relatively close to areas where their preferred mental health services were located. The diversity of options in terms of treatments, professionals, and services was limited within the public system because of the economic realities associated with service provision. Service users Claire, Greta, and Sarah noted that poverty limited choices even further, with Greta stating, “if you're poor you only have the choice of what the mental health system's offering you”. About half the service users had used their own money to access services in the private system, because they felt their choice was too limited in the public or community health system. Given that many of these service users were living on pensions or low incomes, participating in private mental health services represented a serious and significant investment. Amanda noted that part of her ability to be more empowered in decision making was because the range of options for mental health service support had increased significantly. She had struggled to access services because she had to rely on public transport, but noted innovations, such as home-based programs, were much more
in line with her needs and expectations of service delivery.

**Importance of information**

The process to gain power over decision making often meant service users engaged in their own investigations, conscientiously seeking information to build knowledge about their illness and issues and the range of treatments and services available to them.

You get what you want, if you know what you want and ask for it. But if you don't know what you want, you get shit. That's what my experience is from most people that I know in the system. (Tara, service user)

As such, a service user armed with information and able to advocate would have greater decision-making power.

A high number of the service users interviewed had undertaken formal study as a means to build their knowledge. Despite the claim that the emergence of the internet and related web technologies had led to self-informed clients (Shaw, 2002; Solesbury, 2001) the internet was not a popular resource for most of the service users. Only two service users used the internet and tools such as email alerts regularly and strategically to source information pertaining to their mental health issues. A few said they used the internet intermittently, but it was a problematic technology for many because they did not have the computer skills to use it effectively or they did not have ready access to the internet. Six service users regularly sought information from libraries and bookstores. A number had attended conferences on mental health, where they had gained information about mental health treatments, networks, and services, with one service user attending regular conferences as a primary source of information and networking, although she noted the expense of travel and conference fees was often restrictive. Some service
users looked to peer-support groups and mental health organisations for information, requesting specific materials or placing themselves on relevant mailing lists. For Tracey this was important because:

… sometimes you're not ready to read. If you're not well and it's difficult to concentrate then you're not at a point that you're going to be bothered to even go and seek out information. So that's why I think peer support groups and you know, looking at ways to try to engage consumers is just, just really crucial in that … Because it's a step of, it's a first step to you know getting to reconnect into the community and yeah. Yes, information's really important.

Professional health and human service providers, such as psychologists, psychiatrists, and therapists, were important sources of information and advice for most. This was indicative of an effective and collaborative decision-making relationship where professionals shared their knowledge and discussed options openly, as in the process-oriented model of EBP (Gambrill, 2006b; Sackett, et al., 1996; Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). The relationships where this sharing of knowledge occurred stood out as exceptional to service users and were often the relationships service users sought to sustain. For Brian, he did not see that he had any choice in the way he dealt with his mental illness and his only regular interaction and source of relied-upon information was his doctor. General practitioners were cited as an important source of information, particularly in the early stages of diagnosis and when connecting with services. A number of interviewees described the way in which the knowledge and referral mechanisms of the general practitioner impacted on their future service use. A good general practitioner, who listened, was consultative and well-
informed about the range of services and treatments on offer was considered highly valuable.

For most of the service users, there was a clear pattern whereby participation in decision-making and information-seeking activities was limited and deferred largely to professionals early in their experience of using the mental health system or, at times, when their illness was most severe. However, as they moved towards recovery and became more familiar with the health and human services system, they tended to demand more active decision-making collaborations and actively sought information to build their own knowledge, seeing this as a means of building their decision-making power. The exception was Claire who, although she’d become more active in decision making and advocacy as her experience of the mental health system grew, she found she did less reading and investigation as time went on. She did significant self-directed reading early in her illness to explore options and alternatives for treatment, but felt once she had found a medication program that suited her she did not need to continue looking for information to such an extent.

Service providers tended to agree that users of mental health services had limited choice, and were perhaps even more cynical about the qualities of collaborative and empowered decision making. In Cara’s experience, consumers wanted more options and much more information than was generally provided in their interactions with mental health sector professionals. In reference to EBP, she suggested many practitioners had already made conclusions about what works based on the available evidence and simply offered the client what they considered to be a proven intervention without discussion of options.

Service provider Dawn noted the increased accessibility of information regarding mental illness and mental health, particularly through the internet, was
sometimes problematic because consumers were then seeking and requesting treatments and services that were either not available locally or were not appropriate to their specific circumstances. Evidence was not generally considered a significant or influential factor for consumers in their decisions regarding service use.

Fiona noted the most influential factor for her service’s clients seemed to be the service staff members themselves and she was very mindful of the way her opinions and recommendations shaped the decision-making processes of her clients. She also noted a dearth of available information to support clients’ decision making, suggesting:

We have this idea of collaborative therapy or collaborative care planning and stuff like that, but unless they actually have the information to start with and have a knowledge base then, you know, again that's just that tokenism.

Dawn, Samantha, Brenda, and Jacki all suggested, in accordance with the beliefs of most service users, choice was severely hampered by the lack of options available and by the way in which the mental health system was structured. It was generally agreed there simply were not enough resources available for wide choice and many options had such extensive waiting lists they were not realistic options. It was noted, however, if you could afford to pay in the private system then choice was significantly expanded. The actual funding structure of the mental health system was seen as a prohibitive factor to collaborative and empowered consumer decision making, because clients were categorised into funding streams according to diagnoses and this affected the options available. In addition, the competitive nature of funding processes was seen to work against cooperation between service providers, creating a silo effect and limiting the capacity for clients to access a broad or diverse range of options. Brenda and Jacki described factors such as cognitive impairment and court orders as major
challenges for informed decision making, although they considered it vital for every effort to be made to afford empowered, active decision making to service users. They noted it was often necessary to invoke guardianship arrangements and engage caregivers in decision-making processes. They were concerned that service users accessed services because they wanted to comply with professional or court recommendations in order to avoid institutional care or “they've been told that, yeah, this is the service, this is the only service that we've got on offer and this is what we've got and you need to adapt to what we can give you”. The overall perception was that service users needed to adapt to, and work within, a fairly inflexible and complicated mental health system, which added strength to the perception by service users that their decision-making capacity increased as they came to understand the system better and build their confidence and advocacy skills.

Conclusions

The influence of the mental health consumer movement is apparent in the way in which participation strategies have been incorporated into mainstream service settings and consumer-driven frameworks, such as the recovery model, feature in Australian policy. It is not clear, however, whether the adoption of these types of principles in a policy sense has been translated into the type of structural reform required to redress power imbalances and diminish the disparity of participation experienced by mental health service users, as shown in Table 6.1.

Complexities of participation were demonstrated, with service users and service providers generally placing a high value on the involvement of service users in decision making at the policy, service, and individual treatment levels. However, the challenges for informed and empowered choice during periods of severe illness or crisis,
highlighted the requirement for a diverse, creative, and individualised approach to participation, which recognised the dynamic power relationships involved and importance for service users to be able to trust and hold accountable the professionals on whom they relied. The failure to implement diverse and individualised participation strategies to challenge, rather than fit into, the existing structure of the health and human services system, has resulted in exclusionary participatory mechanisms. Service users who lacked the confidence, interest, capacity, knowledge, or health required to function within participatory fora and in participatory mechanisms risked reifying the marginalised identity of mental health consumers. The pressure upon consumer advocates to adapt to existing structures and hierarchies, in which the service user was generally subordinate, in order to have their voice heard and their expertise acknowledged, was demonstrated by the propensity for service users to gain formal qualifications within a discipline that could legitimise their expertise as equivalent to other professionals. However, this also indicated that service users saw knowledge and information as powerful tools in understanding and advocating for greater choice, wherein their own capacity to participate was a privileged position that could help others who were more vulnerable.
Table 6.1 Comparison of policy intent and service-user perception

<table>
<thead>
<tr>
<th>Policy intent</th>
<th>Service-user perceptions</th>
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<tr>
<td>Client-centred, high level of consumer and care input to planning and decision making at the individual level</td>
<td>Limited options (unless able to pay) and therefore little real opportunity for choice</td>
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<td></td>
<td>Dependent on particular workers and the establishment of trusting respectful relationships</td>
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<tr>
<td>EBP related to development of clinical guidelines (practices rather than process)</td>
<td>EBP as practices rather than process led to scepticism regarding EBP’s potential to cater for individual circumstances and alternative approaches</td>
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<td></td>
<td>EBP has value as a tool for accountability and responsible practice</td>
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<tr>
<td>Consumer participation in policy and service decisions as standard practice, in formalised ways, including paid and unpaid roles</td>
<td>Participation practices demand flexibility and high level of skill on part of service users</td>
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<tr>
<td></td>
<td>Formal representative approaches do not suit all service users</td>
</tr>
<tr>
<td></td>
<td>Much participation tokenistic</td>
</tr>
<tr>
<td></td>
<td>Participation of service users has had positive impact and is central to philosophies such as recovery</td>
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</table>

Service users and service providers concurred that the power and expertise of the service user was central to the recovery process, emphasising the highly personal, contextual, complex, dynamic, and individualised nature of the outcomes sought in mental health recovery. While this was seen as problematic when measured against notions of EBP, where research-proven practices were prized, it was actually shown to be in accordance with the early, and more conceptually sophisticated, understandings of EBP as a process (Davidson, et al., 2009; Gambrill, 2010; Sackett, et al., 1996). As such, connections can be drawn between the high value which service users place on information and knowledge, the notion of the service user as expert in their own recovery, and an individualised and collaborative process of EBP. EBP was seen to recognise the need to demonstrate accountability to service users, particularly when their decision-making capacity was compromised and the power of evidence as part of a
participatory decision-making framework.

Efforts at informed and empowered decision making were hampered by systemic frustrations regarding the limited availability of options to meet needs related to mental health. There was a sense that there was no choice to be made because there was little to choose from. Mental health services users have demonstrated historically, and in this study, that they are a force for change to be reckoned with. The rhetoric of policy, particularly at a federal level, and the aspirations of service users seem to align. The challenge is to align decision-making mechanisms and structural frameworks at a funding and implementation level with goals regarding recovery and participation. EBP may well be one tool for achieving this.
Across the diverse and complex web of agencies categorised as human services in Australia, the specific goals and outcomes sought by governments, non-government service providers, service users, the public, and wider society, vary greatly. However, Fraser’s (2008a) theory of parity of participation provides a useful framework for encapsulating the social justice aspirations of human services (and to an extent health services), and in this study was used as a mechanism for conceptualising the success or otherwise of contemporary mental health and homelessness policies and programs. Ultimately it asked, how does practice or policy making enhance (or detract from) the opportunities of individuals or group of individuals to participate in social, economic and political practices of society.

Unlike the model of parity of participation, which derives from citizenship and feminist discourses, thereby having roots in subverting the norm and giving voice to marginalised populations, EBP was driven from a practitioner perspective. EBP gained prominence as a tool for improving the accountability, efficiency and effectiveness of practice and policy making, but its implementation in human services in Australia was limited (Murphy & McDonald, 2004). EBP struggled to gain acceptance because it was [mis]judged as a form of practice that sought conformity to proven practices, rather than a process premised on affording accountability and transparency based on collaborative decision making between practitioners and clients. When conceptualised in this process-oriented way, connections between EBP and participation seem obvious. However, this study has shown that this idealised model was quite different from the way that those
using and providing human services understood EBP and that the actual experience of using human services in Australia was a long way from this type of accountable and transparent approach. The importance placed on evidence-based methods varied among service users, but, generally, factors such as relationships with service providers and the influence of peer support networks seemed to be more highly valued when assessing the quality of a service.

The study examined the potential for principles related to participation and EBP, though deriving from quite different discourses, to be complementary and to enhance and strengthen aspirations towards parity of participation. Terminology regarding EBP and social inclusion gained prominence in policy frameworks in tandem, but they were not necessarily posited as complementary tools. While the study has shown that much of what has been expressed by governments and services in relation to EBP, social inclusion, and participation is jargonistic and rhetorical, there are important, fundamental elements of these principles which are complementary, and which are important to draw out such that, if or when the fads of social inclusion and EBP are superseded, the emphasis on accountability, transparency, fairness, and collaboration is retained.

The case studies were purposefully selected in order to compare and contrast the homelessness sector in which participation of service users was slow to develop and in which EBP was emerging, but struggling to gain a foothold in a complex, multi-provider crisis-model of service provision, with the mental health sector in which the participation of service users had become a core strategy of service provision and which, given its proximity to health and medicine, has had greater exposure to EBP. This chapter explores the similarities and differences across the case studies in order to draw out the answers to key research questions regarding the value and meaning of
evidence to service users, the types of expertise that are important to service users, the meaning and value of participation to service users, and how the concepts of evidence and participation relate to decision-making processes regarding use of human services.

**Case study comparison**

The case studies reinforced findings from the literature that indicate greater participation by service users in decision making, at individual and representative levels, but which has been inconsistent and often tokenistic (Beresford & Croft, 2004; Carr, 2007; Cruikshank, 1999). The type of participation experienced by service users varied greatly across the two sectors. At a representative level, generally, those in the homeless sector were advocating increased participation of service users and were undertaking pioneering roles as service-user representatives on committees and advisory groups. In the mental health sector service users were generally referred to as ‘consumers’, indicating the influence of neoliberal choice in a market place of services, although this label was contested within the sector. Their representative participation roles were far more structured and were often paid positions, although payment was a source of contention. Many had participated in mainstream health and human service agencies, even as employees of these agencies in consumer-designated roles. However, at an individual level there were more similarities in the experience of participation. Both case studies indicated a feeling that collaborative choice and decision-making processes were undermined by the sheer fact that there were no options to choose from. In the mental health sector the qualifying note to this idea was the fact that if you could afford to pay, the choice was greater. For those in the homelessness sector, their inability ‘to pay’ was intrinsic to the situation of homelessness. Table 7.1 provides an overview of some of the key comparisons across the two case studies, which provide the
basis for examining the case study findings in relation to the research aims and theoretical framework.

While both case studies found support for key ideas regarding the value of service-user expertise and the lack of accountability to service users, there were significant differences regarding the way in which service users engaged in formal participation mechanisms. In the mental health case study respondents described their participation in the service sector in paid consumer consultant roles and as part of formal government-funded advisory groups or as part of peer support groups or unfunded activist groups. Some reported that they found that participation mechanisms such as peer support groups and advisory groups did not seem to have a place for them. In contrast, the homelessness sector’s participation mechanisms were relatively new and often unfunded. Advisory groups were emerging as a key strategy. Respondents reported that there was reluctance from the sector to offer paid consumer roles and activities that were funded or supported by government were highly susceptible to the politics of the day. Much of the participation was about relationships with certain service providers who sought their expertise or was about unfunded advocacy activity.

The dynamic nature of decision making was more pronounced in the mental health case study, whereby service users described vastly different capacities and willingness to be involved in decision making at an individual or representative level during periods of illness and periods of stability. Respondents in the homelessness case study did note that their decision-making capacity varied between times of crisis and desperation to periods where they were securely housed, but they tended to consider themselves as effective and capable decision makers at all stages, if given the chance to make decisions.
Table 7.1 Comparison of key findings from case studies

<table>
<thead>
<tr>
<th>Homelessness</th>
<th>Mental health</th>
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<tbody>
<tr>
<td>Emerging service user participation movement, citizen-based rights approach, yet to demonstrate impact.</td>
<td>Strong ‘consumer’ participation movement has led to professional consumer roles and inclusion of recovery and participation in policy frameworks.</td>
</tr>
<tr>
<td>Challenge for participation mechanisms to engage the most vulnerable and move beyond tokenistic gestures.</td>
<td>Paradox of advocating for change from within the system. Challenge for participation mechanisms to recognise individualistic, non-mainstream approaches. Participation mechanisms reify, rather than challenge, stereotypes and stigma and demand high skill levels and adaptability.</td>
</tr>
<tr>
<td>EBP seen to be about research-supported practices, particularly housing first, rather than processes.</td>
<td>EBP seen to be about practices, not processes. As such concerns that EBP contradicts recovery by being top-down and medicalised.</td>
</tr>
<tr>
<td>Understanding of EBP Service users: 3 high, 4 medium, 4 none Service providers: 1 high, 4 medium</td>
<td>Understanding of EBP Service users: 2 high, 6 medium, 3 none Service providers: 3 high, 2 medium, 1 none</td>
</tr>
<tr>
<td>Strong federal policy framework emphasis on EBP, participation, and social inclusion, but fails to translate into implementation strategies at state and regional service provision levels</td>
<td>Consumer and recovery focused policy frameworks at all levels, with varying degrees of emphasis on EBP (and poorly conceptualised notions of evidence)</td>
</tr>
<tr>
<td>Lack of accountability to service users (only recourse to speak with their feet) and decision making seen as arbitrary</td>
<td>Importance of trusting that professionals can make good decisions when service users need to concentrate on getting well (professionals to have ‘done their research’).</td>
</tr>
<tr>
<td>Service users exercising little power in decision making, at whim of providers, little real choice available.</td>
<td>Participation in decision making varies between times of crisis/severe illness and periods of recovery, with mechanisms such as advanced planning a means to retaining power over decision-making processes.</td>
</tr>
<tr>
<td>Service user expertise highly valued by study respondents (but not seen to be valued in actual practice settings) as a tool to improving services, exercising the right to participate and in building the evidence base.</td>
<td>Service user expertise seen as unique and central to recovery. Attempts to legitimise service user expertise through formal education and professionalisation of consumer roles.</td>
</tr>
<tr>
<td>Word of mouth and recommendations of fellow service users were most important source of information (far more important to decision making than empirical evidence).</td>
<td>Doing own research (books, library, internet, conferences, peer support) important during recovery, after moving past crisis stage. Ambivalence about importance of evidence in decision making.</td>
</tr>
<tr>
<td>Experience of service use a long way from ideal types of EBP and participatory decision making - not about making choices, but rather taking what is on offer.</td>
<td>Experiences of partnered decision making were highly valued but there were limited options from which to choose.</td>
</tr>
<tr>
<td>EBP seen as a potential tool for improving accountability.</td>
<td>EBP seen as professional responsibility, although cynicism about the bias of evidence towards medication-oriented treatment.</td>
</tr>
<tr>
<td>Service users saw a role for themselves in research activities and generating the evidence base.</td>
<td>Varied interest in research activities, from experience in leading, designing and advising research to no interest.</td>
</tr>
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</table>
This reflects fundamental differences in the way the mental health and homelessness service sectors are structured. Service providers interviewed for the homelessness case study described the challenges for innovation and collaboration in a sector that emerged as a crisis response, led primarily by charity agencies. Respondents in the study explored their use of a range of agencies which they considered relevant to homelessness, including federal government agencies such as Centrelink, state government agencies such as Housing NSW (commonly referred to as Department of Housing) and a diverse range of non-government agencies such as crisis accommodation services, social housing providers, women’s refuges, drug and alcohol rehabilitation facilities, food vans, legal services and counselling services. Within this broad range of services they had been serviced by different types of professional and non-professional workers, such as social workers, psychologists, community workers, volunteers, administrators, lawyers and caseworkers. Despite accessing a wide range of services respondents generally described similar experiences of confusion, multiple referrals and a limited ability to control or shape the intervention or treatment they received. The homelessness sector seemed to struggle to move beyond a crisis mode of service provision and was rooted in the charity model with its moralistic overtones, paternalism, highly varied levels of professionalism, and perceived lack of transparency, hence the absence of a partnership or collaborative approach to decision making. Instead, service users were treated as beneficiaries and service providers as benefactors, with Mike stating that many service providers responded to input from service users with an attitude suggesting “Don't you dare suggest anything to us because we know what's best for you and you should be grateful that we're even giving you a cup of tea”. In contrast the majority of service-user respondents in the mental health case study had entered the system of mental health services through an admission to hospital or through
their general practitioner. It was after this exposure to the medical sector that they began to navigate, through referrals from medical staff, orders administered by the Mental Health Tribunal or through their own investigation and networking, community-based options (some government funded, some private) such as day programs, psychological therapy, counselling, psychiatry, peer support programs, art, yoga, music, case management and supported accommodation. While the mix of professions varied, and included workers who were doctors, nurses, social workers, psychologists, community workers and administrators there seemed to be a clearer identification of professional roles than in the homelessness sector. Most significantly, however, mental health services had a longer history of consumer advocacy, and consumer-group lobbying had exerted pressure on the development of policy in the sector such that the users of services had, in rhetoric at least, come to be considered as active agents in the decision-making process. Interestingly though, the actual experience of many of the respondents was that their active agency in decision making was something they had to advocate strongly to attain and were only able to achieve when familiar with the mental health service system and when not experiencing significant illness. Some had never had this type of active role in decision making.

Though an outcome of health, social, and economic factors, homelessness was seen mostly as a temporary situation or transitory experience (although this is clearly an oversimplification of what is often a chronic, recurring, and complex social problem). Mental illness, on the other hand, tended to be treated as a lifelong or chronic condition. Whereas an individual might experience homelessness, find secure housing, and move on from that experience, mental illness was seen to play a more enduring role in shaping identity, being more difficult to move beyond in the same way. Rather, approaches,
such as recovery, sought a full and meaningful life (in terms dictated by the service user) of which the mental illness was merely one feature of the individual’s situation.

Commentators such as then Opposition Leader, Tony Abbott, have been criticised for suggesting that homelessness is related to lifestyle or that it is a “choice” (Nader, 2010, para. 4). In comparison, mental illness is treated (and increasingly so) as a health issue and so there is not a perception of the individual choosing the situation, though there is some sense of choice in relation to individualised treatment approaches. This distinction between having and not having a choice in the matter also seemed to contribute to the different approaches to participation in the mental health and homelessness sectors. The users of homelessness services who participated in this study felt pressure to express their gratitude to service providers for the services offered, irrespective of whether the service being offered was important or necessary to the service user. The pathway into homelessness services was complex, difficult, and confusing for service users forced to navigate copious referrals, and to approach a variety of different services for different needs, such as short- or long-term housing, food, clothing, and medical and legal support. For this reason, knowledge built about this complex system over time and expertise gained in using homelessness services was highly valued by service users and by some service providers. Most mental health service users were referred via a general practitioner or hospital through the health services system. As with homelessness services, understanding and navigating the system of mental health services was seen as daunting for newcomers but the capacity to make informed choices improved during the experience of using the system. However, there was a sense that accessing mental health services was a more structured and formal process in which the state exercised enormous power as service users were exposed to legislative processes, such as Involuntary Patient Orders by which a person
may be legally detained in a mental health facility, or Community-based Treatment Orders, whereby the person living in the community may be required to comply with medication regimes and participate in activities such as counselling and rehabilitation (Mental Health Review Tribunal, 2007).

Despite important differences in the nature and extent of service-user participation and the structure of service use between homelessness and mental health services, the terminology of the service user as a consumer with choice was prevalent in both case studies. Service users generally described themselves as consumers. For those taking part in formal advocacy and representation activities, the most common title for their collectives was “consumer advisory groups”. The notion of consumer participation is, however, problematic when empowerment is equated with a market-based choice because the most vulnerable, marginalised, and impoverished groups have no choice and often do not have access to services (Barnes, 1999; Beresford & Croft, 1993; Carr, 2007). Nevertheless, the description of service users as consumers with choices is widely used in Australian social policy. It was unsurprising, then, that most service-user respondents in both case studies referred to themselves or their peers as consumers on at least one occasion. However, almost all service-user respondents across both case studies said they were not able to exercise free and informed choice in regard to their service use. In both case studies, respondents generally had to take the services on offer, with their restricted choices for one or more of the following reasons:

- lack of available service options or information about alternatives
- inability to pay for private services
- urgent nature of needs and no time to wait for the right service to become available
- incapacity to make complex choices due to illness or crisis
• no or limited transport
• residence outside a major city where there was only one or two services available
• illness or ailment limiting physical ability to access certain services, and/or
• ineligibility for certain services.

Effectively, then, these were not consumers with choice or purchasing power within a market of abundant service options. In fact, government monopolised services for which service users and non-government service providers were required to meet stringent eligibility criteria. It took time and experience to learn how to work the system. Some mental health service users were aware of available service options and had gained the financial means (usually their disability pensions) to purchase services in the private sector. They were strong advocates for the services they needed and exercised discretion and control in regard to the public and community-based options they used. The neoliberal concept of the service user as consumer within a marketised service environment, in which services were run on a business model, was embraced by service users for its connotations of power and control, hence its common usage. However, in reality the majority of service users had limited power and control and few options to choose from.

The limitations on choice presented significant challenges for the adoption of evidence-based decision making in the human services. Welfare reform and economic rationalism meant stringent control and distribution of resources where not all options or interventions were available to all service users at all locations. However, evidence-based policy making and representative types of participation have become emblematic of new public management and contracted service provision, making decisions in accordance with best available evidence in partnership with service user groups. This is
somewhat different from clinical decision making and EBP with individuals experiencing diagnosed mental illness when practitioners respond by taking into account the best available evidence and the interests and preferences of the individual, their circumstances and environment. In this study, most service users, when not acutely ill, wanted to review the evidence pertaining to the range of available interventions so as to make informed choices about their treatment, support, and recovery. Some even wanted to do their own investigation to locate evidence on which to base their decisions or to present to service providers, in a few instances, to drive research that would generate evidence to support their informed decision making. These same service users reported that when they experienced heightened states of crisis or illness they wanted professionals to make responsible and respectful decisions on their behalf. At such times, they had no interest in reviewing the evidence. Less common, but also represented in the study, were service users who were not interested in reviewing the evidence at any stage and expected professionals to make good and respectful clinical judgements on their behalf.

Common across both case studies was the value service users placed on trusting and respectful relationships with professionals and human service workers. This was generally seen as more important and influential than the empirical evidence. The other factor common in both case studies, which tended to surpass evidence in terms of relevance and importance in service use decisions, was peer opinion or service-user expertise. The knowledge, insight, and wisdom gained from the lived experience of mental illness or homelessness was perceived to be highly useful when making decisions about service use. For users of homelessness services, this expertise was accessed informally through word of mouth and communication with others experiencing homelessness, often with veterans mentoring the newly homeless.
However, there were urban and regional differences. For example, homelessness was more visible and the peer network was stronger in capital cities, than in regional areas where homeless populations were more dispersed. The advent of consumer advisory groups represented one attempt to provide a formal pathway to service-user expertise targeted not so much at other service users, but at policy makers and practitioners. For mental health service users, peer expertise was accessed in various ways: informally through conversations with other service users, often while hospitalised or formally through peer support groups, consumer advisory and advocacy groups, online forums, and conferences or published works written by mental health consumers. The common threads across the case studies indicate important considerations for evidence-informed modes of practice and policy making because they reveal what is important to service users and the complex and dynamic nature of decision making, which has tended to be oversimplified within models of EBP.

Implementing EBP: Comparison of case studies with survey of social workers

The survey of Australian Association of Social Work members (n=425) conducted for the Australian Research Council funded study Implementing Evidence-based Practice, which ran parallel to this study, supported some of the key findings in regard to service-user perspectives on EBP (Gray, Plath & Webb, 2012). The study focused specifically on social workers, a professional and specific subset of workers in the human services sector with 62.3% holding a bachelors degree and 24.6% holding a masters degree. Given that respondents in this study described various workers they had interacted with, including administrators, volunteers, community workers and various professionals, tertiary-qualified social workers do not necessarily represent the overall perspectives
regarding implementation, but the survey does offer important insight into a group largely employed in human, health and community related service provision and administration. 48% of survey respondents were frontline workers, while 29.6% were in team leadership, middle management or executive level positions. 9.8% identified as consultants. Overall respondents were positive about the concept of EBP, with 26.8% suggesting research findings were extremely useful in their day-to-day social work and a further 56.2% indicating research findings were between moderately to very useful. 29.9% strongly agreed that implementing EBP improved client care, with a further 54.7% agreeing from a moderate to a high extent that this was true. Lack of time was identified as by far the most significant barrier to implementing EBP, with 67.1% identifying it as one of a number of barriers and 25.8% identifying it as the major barrier.

In relation to specific findings from this study, first, the survey responses reinforced that at the coal face of service delivery and policy making understandings about how to implement EBP and about what constituted evidence were diverse and often inconsistent with the definitions and processes put forward by the literature. Respondents in the survey defined evidence in a variety of ways, many identifying research (e.g., outcomes, studies, and reports) as evidence. Other inclusions were practice wisdom (peer and own), training and workshops and conferences.

Secondly, survey respondents indicated that there was little to no demand for EBP being generated from clients (i.e., from the bottom up). 72.4% of survey respondents (n=286) indicated that there was no demand from their clients to be provided with evidence for the treatments or interventions on offer. Among the 27.6% (n=109) who indicated that there was a demand from clients for evidence to be provided there was little consensus on what evidence meant in this context and little consistency
in the approach to providing evidence to support client decision making. It is important to note that for some of the social workers surveyed their ‘client’ was not necessarily a service user, but was another agency or professional group as their role involved high-level consultancy and policy development rather than direct service provision. The responses indicated confusion between information and evidence. Providing verbal summaries or discussions regarding the evidence base for treatments or interventions was the most common means (n=15) of responding to demands for evidence, or fulfilling what was seen as a professional requirement to provide evidence. Ten respondents mentioned that they used the internet or websites as a source of information for their clients or as a recommended source of information for clients to do their own reading. Some provided written summaries of literature, journal articles or other written materials. Only one respondent mentioned the Cochrane Collaboration as a source of evidence to provide to clients.

The survey findings, focusing on a specific subset of human service providers and policy makers, verify the challenges identified in this study for translating the ideal models and aspirations of EBP into an area of practice and policy that is complex and multifaceted. If there is so little agreement and consistency in the way EBP is implemented and presented to clients from the professional perspective, clearly the challenges for already-marginalised service users seeking to gain improved levels of participation and collaboration through EBP are great.

**Parity of participation**

Viewing the case studies through the lens of Fraser’s (2000, 2001, 2008a, 2008b) parity of participation framework, draws attention to three key reformative domains to redress subordination and inequity: redistribution (economic domain), recognition (identity
domain), and representation (political domain) (see Table 7.2). Each of these domains suggests or employs different interpretations of service-user participation: The economic domain uses the language of consumer choice and consumer voice; the identity domain draws on the long history of advocacy within the self-help and service users’ movement; and the political domain represents the writing of consumers – either as members of consumer advisory groups or individual consumer representatives into contemporary policy. However, these categories often overlap and defy discreet categorisation. Far from engaging in reductionist and oversimplistic analyses of inequality and inequity, Fraser’s framework provides a useful benchmark against which to monitor the impact and effectiveness of policy reforms vis-a-vis service-user participation within these key domains (see Figure 3.1). Figure 7.1 isolates the means through which different understandings of service-user participation within the economic, social (identity), and political domains implies different approaches to or mechanisms for service-user participation.

Interpretations and approaches within the economic, social, and political domains also lead to differential priorities regarding outcomes. Within the economic domain, one of the key impacts of neoliberalism is contingent funding based on concrete data reporting on policy and program efficiency and efficacy. This requires specificity and measurable criteria of goals (purpose) and outcomes (products). In short an economic rationality requires the ability to delineate measurable outcomes. This language, however, is more characteristic of the EBP than the service-user discourse (see Chapter 3).
As seen in Chapter 2, critical analyses of EBP question positivistic notions that all goals can be reduced to measurable outcomes since choosing or deciding upon outcome measures is often a highly political and context dependent process (Hope, 2002; Sapey, 2004). Measuring success in terms of the achievement of predetermined outcomes in itself requires the reduction of complexity. It is a political process serving the interests of diverse stakeholders, such as funding bodies, service providers, service users, and community members.

Fraser’s framework measures the extent to which a policy or program reshapes redistribution to reduce inequality, recognition to include minorities, and representation to give marginal groups a voice. These impact measures can be applied at a macro structural level or micro intervention level and across different program types and service areas, irrespective of the outcomes sought by stakeholders. It presumes, however, that reducing inequality or inequity is a desirable outcome. This goal sits at the heart of social justice.
Table 7.2: Challenges to parity of participation

<table>
<thead>
<tr>
<th>Economic</th>
<th>Identity</th>
<th>Political</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Homelessness case study</strong></td>
<td><strong>Stereotypes regarding intelligence, education, mental health, substance use, parenting ability</strong></td>
<td><strong>Lack of funding for advisory/representative groups</strong></td>
</tr>
<tr>
<td>Unable to access housing market due to poverty or poor rental history</td>
<td>Documentation (lacking identification or struggling to complete paperwork)</td>
<td>Service providers/workers speaking on their behalf</td>
</tr>
<tr>
<td>Limited employment opportunity (due to unstable housing or lack of work experience/qualifications, illiteracy)</td>
<td>Lack of connection with workers</td>
<td>Personal (often painful) stories shared publicly with unclear purpose</td>
</tr>
<tr>
<td>Unable to afford social and recreational activities</td>
<td>Restrictions on freedom because of identity as drug-user (e.g., strict rules)</td>
<td>Inaccessibility of consumer groups (lack of knowledge, lack of access to technology)</td>
</tr>
<tr>
<td>Automatic housing payments deducted from pensions and allowances</td>
<td>Being excluded from services because of age (e.g., too young even though living independently on streets)</td>
<td>Consumer groups and forums managed by service providers (who often handpick participants)</td>
</tr>
<tr>
<td>Volunteer and advocacy work often unpaid and unrecognised as “work”</td>
<td>Criminal history limiting employment and housing options</td>
<td>Lack of dispute resolution or complaints mechanisms (such as Ombudsman)</td>
</tr>
<tr>
<td>Inefficient service provision using up limited resources</td>
<td>Workplace discrimination (unlikely to even get a job interview)</td>
<td>Difficulty protecting legal rights (such as reporting incidents of assault) due to attitude of authorities and logistical problems for following up with no fixed address</td>
</tr>
<tr>
<td>Level of understanding and compliance required to access Centrelink benefits</td>
<td>Being pitied or treated as incapable by service providers and people in public</td>
<td>Lack of action arising from participation activities</td>
</tr>
<tr>
<td>High cost of living (limiting choices on food, transport, housing)</td>
<td>Shame and fearing to take part in everyday interactions (such as walking down street)</td>
<td>No recognised/paid roles for service users as consultants or advisors</td>
</tr>
<tr>
<td>Living below the poverty line</td>
<td>Being perceived as a troublemaker if you speak up (and being blacklisted)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Losing friends/friends not understanding</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Maintaining safety and wellbeing of children as a homeless parent</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Being looked at with fear or caution by public</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health (physical and mental) impacts, including death</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Loneliness</td>
<td></td>
</tr>
</tbody>
</table>
| Mental health case study | • Dependence on pensions and government allowances  
• Challenges for participating in a workforce that is not flexible, compassionate and supportive  
• Maintaining secure housing with limited income or with pets  
• Unable to afford preferred private services  
• Limited transport options  
• Loss of Centrelink payments if casual or part-time work exceeds threshold  
• Need to live close to services | • Effects of medication on decision making capacity  
• Losing children/parental abilities questioned  
• Being referred to specific activities for people with mental illness, rather than participating in mainstream activities (e.g., yoga)  
• Physical health neglected as mental health prioritised (e.g., weight gain from medications, smoking, GP only checking mental health and failing to check physical health)  
• More recognition and acceptance now due to public figures identifying with mental illness  
• Media portrayals of people with mental illness as violent and dangerous  
• Public perception as bludger  
• Physical conditions limiting access to services and daily activities  
• Challenge for young people to speak up for themselves  
• Anxiety about public perception exacerbated by illness (such as paranoia)  
• Not wanting mental illness to dominate identity | • Lack of authority to question medication  
• Community Treatment Orders  
• Mental Health Tribunal making decisions regarding service use  
• Lack of payment for advocacy and advisory activities  
• Lack of access to technology required to participate in some forums  
• Disagreeing with views of other consumers and so not feeling a place in representative groups |
Both case studies supported the value of a parity of participation approach to social justice. Service users described subtle and complex ways in which people who had experienced homelessness or mental illness had been excluded from full participation in Australian society or had felt that their economic, social and political opportunities were impeded.

There is a clear dominance of identity-related concerns for the respondents in this study, related to the way in which they are perceived and treated in society and within services. However, mental illness and homelessness were not only issues of identity, but encompassed a range of economic, social and political concerns that would need to be considered in any comprehensive analysis of an intervention’s effectiveness. For example, a homelessness program’s tangible goal might be the long-term accommodation of a target group or population matched by the provision and retention of accommodation as an indicator of success or program outcome. While this befits programmatic evaluation, it does not consider whether a person’s socioeconomic or health status has changed or whether concrete structural change has been achieved.

Further, such a program outcome does not mention the way in which homeless people are treated within the system. Homelessness service users said they were treated like “non-citizens” (Melanie), devoid of legal rights. There were economic impediments to their participation: reduced employment opportunities, social activities, and ability to find affordable housing. Poverty (maldistribution) was closely intertwined with homelessness. Identity issues (misrecognition) led to stigma and discrimination, and was personalised as a sense of shame for being homeless or mentally ill. Recognition was limited to peers, other homeless or mentally ill people, who tended to band into groups of like experience. Individually service users felt they were not afforded the
same protection and recourse to justice as citizens in mainstream society but as a group they felt more secure.

More complex, however, in neoliberal welfare environments is the notion of participation. Contemporary policy comes with participation requirements usually surrounding economic participation or paid work: Termed “activation policies” (Bonvin, 2008, p. 367), the goal of neoliberal reform is to move people away from welfare and into work. In the service-user discourse, participation is construed as “having a voice” or “having a say” in service provision. It implies choice and control in decision-making processes. However, in reality, choice is restricted: people may be housed, but not in a location of their choosing or in proximity with important social support networks. Consumer participation within neoliberal welfare reform has policy connotations and lacks the activism and transformative potential of old-style participation within the welfare – social justice – discourse (see Figure 7.1). Full participation, whether as a citizen or consumer, means having legal democratic rights and an equal and fair chance of having these rights fulfilled, i.e., parity of participation.

The mental health case study also showed that service users were not necessarily concerned primarily about the mental illness per se. Many were in recovery (their term) from, or were managing their illness through effective medication regimes or coping strategies. As already mentioned the recovery model is highly individualised or personalised and implies self-responsibility for healing. While absence of symptoms or reduced incidents of hospitalisation may be tangible indicators of success for a service provider, or indeed for some people, for others these may not be priorities for recovery and their individual, personal goals, which might pertain to personal relationships, physical health, or a myriad of other factors, may be more relevant indicators within a recovery framework.
Challenging the stigma associated with mental illness – misrecognition – meant overcoming feelings of powerlessness at being treated by professionals in the health and human service sectors as incapable or incapacitated. Struggles for recognition were part of the history of the mental health consumer movement. However, there were problems of a homogenised identity rooted in mental illness, which deflected attention from health inequalities and the high incidence of mental illness among people with limited access to education and economic participation due, among other things, to discrimination in the workplace towards people with mental illness and the challenge of sustaining employment in inflexible and dispassionate work environments. Reliance on state pensions and income allowances compromised the ability of service users to choose treatments and even limited the geographical locations where an individual could live to be near affordable, accessible services. These unintended consequences - positive or negative - are often overlooked in regimes where measurable outcomes like reduced hospitalisation or decreased costs are prioritised. These priorities are often combined with principles pertaining to client-centredness, empowerment, recovery, and strengths-based approaches, all of which imply a degree of self-responsibility or self-care (Gray, 2010).

While EBP is not a tool for social justice it is a mechanism for greater accountability and transparency and can usefully be considered within Fraser’s parity of participation model (see Figure 3.1). By examining EBP in conjunction with the service-user participation discourse (as a specific mechanism or group of activities aimed at achieving parity of participation), the tensions between professional interventions and self-help initiatives can be reconciled in the shared aim of increased accountability, transparency, and knowledge co-production within the human services sector. The research question of whether evidence - unhinged from participation and
empowerment - can enhance effectiveness is central to socially just policy and program interventions. The experiences and aspirations of service users in this study highlighted congruencies and contradictions between the principles of service-user participation and EBP. Ultimately, the study gauged how practice and policy making could be realistically shaped so that accountability, transparency, and co-produced knowledge were, indeed, experienced at a service-use level.

**Value of evidence to service users**

The experience of service users across both case studies was a long way from the idealistic notions of EBP theorised by Gambrill (2006b) and from the evidence-based policy making espoused in policy documents such as *The Road Home* white paper on Homelessness (Australian Government, 2008a). Some proponents of EBP perceived an emerging bottom-up demand, whereby human service users expected practitioners to have ‘done their research’. However, there has been a longstanding distrust of professionals in the self-help service-user movement with users doing their own research rather than relying on, or trusting professional wisdom or expertise (Shaw, 2002; Shlonsky & Gibbs, 2006; Solesbury, 2001). This type of bottom-up demand was not evident in this study. For some service users, the lack of a bottom-up demand for EBP was due to a lack of skills, capacities, and resources to generate a demand. For others, EBP did not include the types of expertise and evidence that were meaningful to them. Research participants in both case studies were generally unclear about what was meant by EBP and what constituted evidence. However, they did expect practitioners to be up to date with the latest research and to shape their practice accordingly.

The hierarchy of evidence is a fundamental, but also a contested, tool. It is fundamental because it is via the application of the hierarchy of evidence that
practitioners are able to critically appraise bodies of evidence. It is via the hierarchy of evidence that EBP distinguishes itself from informed practice based on a wide array of information sources to guide decision making, including service-user experience. The classification of rigorous and reliable evidence into a hierarchy is a defining feature of EBP. However, the notion of best available evidence implies an evidence continuum with reliable gold standard evidence at one end and practice wisdom at the other (Sackett et al., 1996).

The notion of service-user expertise has been poorly conceptualised within EBP generally and within the hierarchy of evidence in particular. While some models of the hierarchy include service-user opinion on the lowest rung as a type of expert opinion (Fraser et al., 2009, see Figure 2.1), for others the question of client values, interest, and expertise continues to pose questions and concerns for the evidence hierarchy (Davidson et al., 2009; Gould, 2006). This is perhaps central to EBP’s failure to gain traction within the human services sector and align effectively with principles of participation. In response to the failure of positivistic notions of evidence to effectively consider the complexity and diversity of social care services in the mental health sector Gould (2006) proposed a framework that encapsulated qualitative and quantitative approaches to knowledge, with respect to highly individualised and population-based experiences. Within such a framework there is a place for service-user expertise at a representative (general) level and also in respect to individual experiences, while recognising that both quantitative and qualitative methods are useful, depending on the research question.
Service users and service providers in both case studies saw the knowledge gleaned from the lived experience of mental health and homelessness as a unique and highly valuable type of expertise or evidence that should inform practice and policy decisions at all levels. While some reservations were expressed about the potential for service-user expertise to be misconstrued to support individual and sometimes misguided agendas, most believed real reform to services could only be achieved by drawing on the insight and knowledge of service users themselves, who had a unique contribution to offer.

Service users sought to gain legitimacy for their lived-experience expertise through studying knowledge of their condition. Mental health service users recruited to participate in professional forums were expected to possess high levels of literacy and competency to undertake formal consumer participation roles. If their expertise were to be respected, they quickly realised the utility of qualifications putting them on a par with the service providers with whom they worked. Engaging in formal study, as seen with at least two participants in the homelessness study and with at least five in the...
mental health study, was part of the pathway to becoming a professional and serving others so that their own negative experiences would not be repeated. However, it was also a means of addressing the unresolved and problematic, yet potentially transformative power of service-user expertise.

It is perhaps not surprising that people considered their own knowledge and experience intrinsic to the decision-making process. But the fact that this notion of service-user expertise emerged so strongly from discussions about EBP with both service users and providers suggests an untapped resource. Part of this pertains to the right of service users to have their interest, experiences, and knowledge respected and validated within EBP. Part pertains to their progression towards independence and self-reliance as per emancipatory, participatory, service-user approaches (Beresford & Croft, 2004; Sapey, 2004) which have, in any case, become the goal of neoliberal welfare. There was a clear sense across both case studies that research and evidence-based practice and policy making would be more successful if such strategies recognised and engaged with the expertise of service users. At the level of individual interactions with services, Sackett et al.’s (1996) original notion of evidence-based medicine considered evidence in tandem with practitioner expertise and client values and interests. Gambrill (2006b) saw EBP as a client-centred process. However, the relationship between EBP and service-user expertise still seems unresolved. First, misinterpretations of EBP have seen its focus move towards practices rather than process. It has been misconstrued as those practices which can be shown by research to work, thereby overshadowing professional expertise and client interest as envisioned by EBP pioneers (Gambrill, 2010; Thyer & Myers, 2011). Secondly, EBP has tools to support the critical appraisal and application of empirical research in practice. Primarily these are the process of systematic review, which has been the centrepiece of the Cochrane and Campbell
Collaborations, and the hierarchy of evidence (and developments on this, such as Daly et al.’s (2007) hierarchy of qualitative evidence, see Figure 2.2). These tools help clarify how a policy maker or practitioner might do EBP. There is no such tool for suggesting how professional expertise or client values might shape or feed into the process. Instead this is implied as an intrinsic component of the way practice is conducted. However, the clear experience of service users in this study is that the implied and assumed process of marrying the evidence with client values is a very long way from actual practice. In fact, neither evidence nor service-user expertise seem to have featured strongly in the way mental health and homelessness services were shaped, from a service-user perspective. For service users, the demonstrable absence of evidence-informed practice and policy making was not as problematic as the demonstrable absence of service-user expertise to inform practice.

For those who understood EBP in accordance with definitions from the literature, there was cynicism about the potential bias of evidence. While the hierarchy of evidence was an attempt to reduce the potential for bias of evidence and maintain rigour, it was seen by some service users and providers as elevating randomised controlled trials and thus limiting agencies’ capacity and resources to produce reliable evidence. In the mental health sector, the hierarchy of evidence privileged pharmacological and medical treatment because the organisations seeking to increase uptake of these types of interventions were those able to afford to fund and report on clinical trials. Resistance to EBP’s implementation in the mental health sector was at least partly related to the perception that EBP supported a medical rather than a social model of mental health and that the types of processes and strategies associated with recovery were much more difficult to measure or produce evidence for. As such, the
trustworthiness of evidence might be enhanced if it could be shown how the hierarchy of evidence was used in tandem with professional and service-user expertise.

The service users and providers interviewed in this study tended to agree on the importance of service-user expertise, the failure of EBP to consider service-user expertise, and the contested nature of evidence. However, the service providers noted that most of their peers working in the sectors did not share the same regard for service-user expertise and looked internally for evidence to support practice. Because participation in this study was voluntary and participants self-nominated, it is likely that the nature and subject matter of this research project attracted those service providers who considered EBP and service-user participation as important.

Various commentators have identified a growing tendency, particularly in the health field, for service users to be more informed about the issues for which they are seeking assistance, largely due to the huge amounts of information now available on the worldwide web (Powell, Darvell, & Gray, 2003; Shaw, 2002; Stilgoe, Irwin, & Jones, 2006). But most of the participants in this study had limited access to the internet, hence because internet-based technology was increasing so too were disparities in participation, creating a digital divide.

Users of homelessness-related services did not demand EBP nor were they able to make any demands on the system. Instead, they had to take what was available. Far from demanding that practitioners demonstrate evidence to support their recommended interventions, these service users felt that they were expected to be grateful and compliant in order to have their basic needs met.

Users of mental health services, however, seemed more involved in their demands for EBP. In the early stages of their illness and at their periods of acute illness, the demand was unspoken: Service users expected that professionals would be well-
researched and trustworthy and able and prepared to act in their best interests. However, as service users moved towards what they described as recovery or stability, or as they built their knowledge and confidence regarding their mental illness, and their ability to manage it, the demands upon service providers became more explicit. Through engaging with peer networks, reading, trialling new treatments and techniques, attending conferences and other such activities, many of these service users became savvier in their approach to service use and had expectations of a collaborative, informed approach to decision making. It must also be remembered that mental illness afflicts people from all social and economic strata and levels and types of education and professional experience vary greatly; this is not a homogenous group (Lammers & Happell, 2003). While not necessarily demanding EBP per se, they wanted a more informed, transparent, accountable, and empowering approach to service users, many of whom had done their research. However, again there was a sense of resignation regarding the limitations of choice in service options.

Therefore, a bottom-up demand for EBP was not found in this study. Rather EBP was misunderstood or seen as unsympathetic to service users’ goals and lived-experiences and discrediting of types of knowledge they saw as important to decision making. There was little capacity to access the resources and information sources that would generate meaningful discussions about evidence. Service users felt that they often, especially at times of heightened crisis, had little capacity to demand anything of service providers. The notion of a bottom-up demand for EBP implies a level of collaboration, empowerment, and choice that was simply not experienced by most of these service users.
Roles for service users in practice, policy making, and EBP

The experiences of the service users were so far removed from the EBP model that it was difficult for them to conceive of their roles in this way. However, in looking at a number of existing service-user practices and aspirations, there are indications of possible coherence between the role of service users and modus operandi of EBP.

One of the overwhelming messages across both case studies was that in periods of crisis, the crisis itself was all-consuming and the service user needed to be able to focus on getting through that period, whether that be about getting well, getting housed, or resolving a myriad of related personal difficulties. However, this did not preclude a participatory approach to EBP at times of crisis. In fact, the loss of control and feelings of powerlessness experienced during times of crisis often exacerbated their problems. Service users wanted respect, to be treated with dignity and humanity, and to be assured that their values and wishes were understood and taken into account in service responses. They did not want to read extensively or undertake complex decision-making processes involving the critical analysis of evidence during an acute crisis. Some people did not want to do these things at any stage. However, there seemed to be agreement that, minimally, their role in EBP during periods of heightened crisis should be to access services based on relevant evidence, which reflected their personal preferences and values. The notion of informed choice retained its value in crisis situations, in fact perhaps more so as people had to rely on professionals when they were most vulnerable.

The types of information needed or demanded and the way in which the information was provided would need to accord with the individual’s circumstances and capacities at a given time.

Service users did not expect to be engaged in a process of EBP at an individual service level because their actual experiences of service use had not indicated this as a
possibility. However, once the idea was introduced many were interested in EBP. They did, however, expect that they would be included as active participants and partners, or even leaders, in the decision-making process in accordance with their capacity at a particular time.

To reiterate, service users are not a homogenous group. Therefore, expectations, interests, and capacities regarding their roles varied greatly. For example, some service users relished opportunities to read and actively sought out material to inform themselves about their condition, including through tertiary and even postgraduate study. For others, barriers such as illiteracy and lack of internet access meant that reading or accessing information was problematic. They therefore sought second-hand information to support their decision making through peers, verbal communication with workers, and in graphic or multimedia forms. Others still were not interested in learning or knowing more about issues such as homelessness or mental health any more than was necessary to sustain their day-to-day functioning. It is this heterogeneity that makes representative types of participation problematic. A generic approach to the inclusion of service users does not sufficiently account for their diversity. As such, strategies such as inclusion of service users on systematic review panels (Carr, 2006) can only be one small part of a participatory approach. In general, there was little expectation that service users would be engaged in evidence-based processes because there was little exposure to and awareness of these processes. However, based on activities that participants had been involved in as service-user representatives, there was significant interest in contributing to research and this was seen as an appropriate and important role for service-user representatives and advocates, as discussed later in this chapter.

The case studies highlighted the way in which neoliberal ideals of consumer choice and control supported the participatory aspirations of some service users with
will and capacity to take on this choice and control, while potentially marginalising even further those individuals with complex and chronic needs treated, as they conceived, as non-citizens. Australian social services are moving towards the individualised, managed-care, neoliberal models of the United Kingdom social services. Proposed reforms to the disability sector may see those people funded through a new National Disability Insurance Scheme, receiving individualised support packages that allow choice over service providers and control over expenditure of a personalised budget (Australian Government Productivity Commission, 2011). The fact that these types of reforms are emerging within the health and social services sectors, such as disability and mental health, is indicative of the relationships between participation and advocacy. In sectors where service users have recognised roles as consumer advocates, strategies to support more independent decision making have emerged the strongest. The experience for users of homelessness services is far from a user-controlled model, and the needs for people with complex and multiple issues related to health, finances, housing, and personal relationships are more difficult to envisage in such a neoliberal model given the strong finding from this study that the willingness and capacity to control decisions depended on a complex range of factors. The question remains as to how supportive structures for people with complex needs might be empowering within contemporary neoliberal services.

The case studies indicated a range of roles and mechanisms for service-user involvement, from paid roles within health agencies in the mental health sector, to individual, independent, and personal modes of advocacy. This diversity of experiences and activities is important, and perhaps central to the way in which a participatory model of EBP might be conceptualised, because one of the key messages across the two
case studies was that notions of participation were highly individualised and as diverse as the individuals accessing human services.

Figure 7.3: Roles and mechanisms for participation

- **Redistribution (economic)**
  - Consumer voice (purchasing power)
    - Purchase private services
    - Paid consumer roles
    - Leading research (to influence policy and resource allocation)

- **Recognition (social identity)**
  - Service-user activism and advocacy (group or individual)
    - Self and peer advocacy
    - Public presentations
    - Awareness campaigns and events

- **Representation (political)**
  - Consumer advisory groups or consumer representatives
    - Consumer consultants and advocates
    - Representatives on steering committees
    - Funded and unfunded advisory groups

The importance of service-user expertise was consistently affirmed thus challenging conventional approaches to EBP and service-user participation. This unique expertise was seen to be integral at a representative level, such as consultation with representative groups of service users or membership of a service-user representative on management committees, and also at an individual level. The notion of the service user, client, patient, or consumer as expert in their own illness is not new, but it has yet to be reconciled with evidence-based practice in health and human service delivery (Davidson
et al., 2009; Fisher & Happell, 2009). Hence this study found that, from a service-user perspective, EBP had not gained real traction in health and human service practice and policy making because of its failure to take account of service-user expertise as evidence. EBP, as the name implies, is a tool for practice and as such its development has focused on practitioners and their role in the clinical decision-making process (Dore, 2006; Gambrill, 2006a; Moseley & Tierney, 2005; Mullen et al., 2007). However, by affirming the role of service users and a place for service-user expertise in EBP, the process might be more effective if focused on individualised personalised outcomes and open to qualitative and collaborative methods of knowledge development, rather than the objective positivistic focus on standardisation, rigour, efficiency, and consistency as averred by its critics (Denzin, 2009; Dore, 2006; Hammersley, 2003; Luitgaarden, 2007).

This study supports earlier work on the role of service users in research (Baxter, Thorne, & Mitchell, 2001; Beresford, 2007; Beresford & Evans, 1999; Braye & Preston-Shoot, 2005; Carr, 2006; Davis, 1992; Entwistle, Renfrewe, Yearley, Forrester, & Lamont, 1998; Epstein, 2004; Faulkner & Thomas, 2002; Griffiths, et al., 2004; Hanley, Truesdale, King, Elbourne, & Chalmers, 2001; Nelson, Ochocka, Griffin, & Lord, 1998; Oliver, et al., 2004; Trivedi & Wykes, 2002; Turner & Beresford, 2005). Many mental health and homelessness service users had participated in research-related activities, such as designing and conducting surveys, leading participatory action research projects, consulting and advising academics on research design, and acting as conduits for researchers to access participants. Some had also participated in related activities, such as program evaluation, presenting at conferences, and acting as advisors to competitive funding processes. It is highly unlikely that any of the research-related activities in which these service users had taken part would constitute EBP, as per
existing definitions. The rigorous methodology required of EBP was generally not an important or intended part of these activities. However, a number of the activities described were quite mainstream, with far-reaching and significant consequences, such as the homelessness street counts and MH COPES (City of Sydney, 2010; Doyle, Coleman, Oakley, & Malins, 2009). Importantly, most service users considered participation in these types of activities, either as researchers or as research participants, an important component of their work as service-user representatives and advocates. They acknowledged what proponents of EBP have failed to: that research may lack relevance, applicability, and substance if it does not connect with, or in some way reflect the experiences of the people it seeks to describe. This is not necessarily a call for emancipatory or participatory research designs, but for recognition that there needs to be a balanced perspective within research. Claiming systematic reviews of randomised controlled trials as the benchmark risks disregarding qualitative and user-informed evidence that may still retain the rigour essential to EBP.

In reality, service providers interviewed for this study suggested that what they considered to be evidence for practice was diverse, including statistics, client feedback, journal articles, and evaluations and reports, a finding also supported by the survey of AASW members. Inclusion of evidence was highly dependent on what was relevant, accessible, and meaningful to them and their clients. In effect, the hierarchy of evidence was irrelevant if practitioners and policy makers were not aware of it, as this study suggests, and if they did not consider the hierarchy pertinent to their work and the aspirations of their clients.

Experiences such as those of the SCIE (Carr, 2006; Coren & Fisher, 2006) in the United Kingdom indicated the potential for service users to participate in formal evidence generation or research processes, such as systematic reviewing, and authors
such as Beresford (2007) have frequently recommended models of emancipatory or participatory research and demonstrated the potential for service users to lead research projects. Certainly those service users interviewed who had participated in activities such as the street counts, MH COPES, and user-led research projects had demonstrated their willingness and capacity to contribute to research activities. However, what this study has also brought into question is the meaningfulness of the participatory mechanisms in place. There is potential for participation in EBP to reinforce strategies that “act upon others by getting them to act in their own interest” (Cruikshank, 1999, p. 68). Service users interviewed for the homelessness case study did not offer the same level of cynicism or concern about participatory practices and their propensity for tokenism as those interviewed for the mental health case study who were taking part in well-established forums and activities and had a relatively long history of service-user involvement. However, homelessness service users did express concern that the type of advocacy and representation work they were involved in was not accessible to most of their peers. Simply adding service-user representatives to existing research teams and committees did not affect the type of structural change envisaged by the concept of participatory parity.

To adopt participatory parity as a framework for practice implies representative types of participation are insufficient. This is not to suggest that such strategies are not an important means of gaining service-user input and seeking service-user expertise. These strategies may in fact be important vehicles for service users to advocate structural change. However, as participants in this study, such as Paul in the homelessness case study and Greta, Elizabeth, Jack, and Brian in the mental health case study attest, so-called participatory mechanisms can be exclusionary for those whose interests, capacities, and beliefs do not align with participation mechanisms on offer.
Individual approaches to participation and EBP are important, because it is at the level of individual interactions with services that decisions are made, or, according to the perception of participants in this research, made for an individual. Here Gambrill’s (2006b) notion of EBP as a “decision-making process and philosophy” (p. 215) is highly relevant, as it establishes the ideals for an individualised and collaborative approach as the antithesis of an authority-based professional model of practice. While Gambrill (2006b) emphasises the original evidence-based medicine model’s integration of client values and preferences, she also suggests that EBP is a mechanism to manage the challenges of relying on client preferences, because client intentions and stated preferences are often quite different from the actions they take. In considering the interrelationships between client values, research evidence, and professional expertise, Haynes, Devereaux, and Guyatt’s (2002) model has been cited to demonstrate that clinical expertise requires engagement with three domains: client values and preferences, clinical circumstances as judged by professional clinicians, and research evidence (Gambrill, 2006b; Mullen et al., 2005). This model emphasises EBP as a more complex process than simply identifying which practices can be substantiated through research and highlights the individualised nature of the process.

The application of EBP and participation during crisis periods is challenging to such a framework. Participants in the mental health case study offered several ideas as to how this was currently being managed. One was the employment of service users in advocacy and support roles, such that when individuals needed to focus on resolving a crisis, a fellow service user with insight into the lived experience and with service-user expertise could mediate in their interactions with staff and advocate and support as necessary.
The second was the use of a personal management or Ulysses plan. This is a plan made between the service user and care providers during a time of good health and stability, which outlines the service user’s priorities and preferred options for treatment during illness, when decision making capacity may be impaired. This type of advanced planning allowed the service user to indicate preferred strategies and actions for dealing with crises during stable periods of good health. This was quite different from relinquishing control and actually demanded a higher level of accountability and transparency, because, as service users expressed it, they needed to know that the professionals they were working with were willing and able to make good decisions on their behalf in keeping with their values and unique circumstances.

Ultimately, however, across both case studies the relationship with workers was crucial to a person’s feeling of empowerment throughout a crisis period. In the
homelessness case study, those service users who had a caseworker, or similar professional support person, to advocate on their behalf and represent their needs, felt that the system had served them well. In the mental health case study, where specific caseworkers, psychologists, or doctors had listened to their needs, goals, and preferences and acted on these, service use was described as a positive or successful experience. In general, service users described successful relationships with workers as ones that were developed and sustained over a number of years. However, others also emphasised the importance of interactions with other staff, such as ward nurses at psychiatric hospital units and Centrelink receptionists, that could have an enormous negative or positive impact on the individual’s perception of the service and whether they felt empowered or respected. The key message was that it was not a particular tool or method of practice that stood out for service users as key to a successful intervention, but rather relationships and personal communication.

The notion of EBP as a decision-making process aligns closely with a participatory collaborative approach. However, three points stand out in regards to Gambrill’s (2006b) conceptualisation. First, the actual experiences of the service users involved in this study were a long way from this type of transparent, collaborative, evidence-based decision-making process, so it would seem that despite its potential, there was something problematic or unrealistic about implementing this type of approach. Secondly, the idea of EBP supporting the engagement of service users as “informed participants” (Gambrill, 2006b, p. 225) assumed a capacity for service users to comprehend and interpret information gleaned from evidence that might be unrealistic in certain circumstances, and in some situations being respected, cared for, and listened to might be more important than being informed. Thirdly, the emphasis on a decision-making process presupposed that there was a decision or choice to be made
on the part of the service user and the practitioner. Most of the service users in this study indicated that there was in fact little or nothing to choose from. The kinds of decisions being made at policy level about the allocation of resources to particular models of support and treatment dictated the options available to service users. Decisions were more strongly influenced by accessibility, availability and affordability of services rather than by the demonstrated effectiveness or efficacy of a model of treatment and support.

Idealistic notions of EBP expressed in policy documents, such as *The Road Home* white paper on Homelessness (Australian Government, 2008a) emphasised the value of evidence in improving the effectiveness, efficiency, and accountability of human services. Such policies acknowledged major failures in the delivery of services to marginalised and vulnerable Australians with complex needs and posited EBP as a mechanism to address these failures. However, without conceptualising the role of services users in the process and without considering how such an evidence-based approach might be implemented at the service provision level, the policy failed to translate into meaningful practice and failed to noticeably expand the decision-making capacity or options for service users at the most vulnerable extreme of society.

**EBP and improved parity of participation**

The key factors emerging from the case studies for a revised model of evidence-informed participatory practice and policy making based on parity of participation are discussed below. This proposed model is considered in greater depth in Chapter 8, where specific components and steps to operationalise the model are explored.
What participation meant for service users

Respondents in both case studies emphasised the disparity in participation for mental health and homelessness service users in Australia. The disparity in opportunity manifested in various ways through difficulty to attain or sustain employment, compromised access to legal protection, financial poverty, poor physical health, limited control over where to set up home, and a general sense of feeling different or separate from others in mainstream society. The aspiration to maintain stable, secure housing or maintain good mental health was imbued with the aspiration to full citizenship and participation in Australian society. Fraser’s (2001) notion that participation was not just an issue of identity or social acceptance, but also required significant attention to the economic and political domains, held true for these respondents. Nevertheless, identity was at times over-riding for these respondents who bore the brunt of stigmatisation, labelling, marginalisation, and misrecognition. Recognition and acceptance was thus crucial to enhancing parity of participation. This was most evident in the mental health case study, where the experiences of participation in formal mechanisms, such as advocacy and advisory groups and representative committee membership, were more strongly established, but was also an idea expressed by respondents in the homelessness case study. Those who participated in representative and advocacy work largely did so because of a sense that their unique service-user expertise and experience could contribute to an improved experience for others in similar positions in the future. They also believed that the experience of participation had provided them with skills and confidence that supported their own recovery and development, whether personal or professional.

Historically, service-user participation has been conceptualised from a citizenship and human rights perspective, or more recently from a consumerist
perspective. Authors such as Beresford (Beresford, 2007; Beresford & Croft, 1993) saw participation as a highly political means of empowerment by which service users exercised their right to be active in decisions affecting them, but which also served as an end in itself by building skills and confidence for the individual gain of the service user. These notions of participation as a right and also as a tool for personal (and professional) development held true for a number of respondents in the case studies. In the homelessness case study the newly developing service-user advocacy groups in Australia were often supported by public interest and legal services, on the premise of participation as a human right. Certainly a number of respondents noted that their experience of participation was one that had had significant personal benefit and many, in both case studies, described feelings of increased confidence and purpose. Advocacy, even when practised at an individual or personal level rather than at a formal representative level, was an act that allowed people to challenge stereotypes and grow more comfortable in their own identity as a ‘mental health consumer’ or ‘homeless person’. Some respondents saw potential for their participation as a professional development tool, that would enable them to act as skilled human service sector workers in the future, particularly in the mental health case study where paid consumer roles were common, but also in the homelessness case study where respondents such as Penny, Rodney, and Steve actively sought employment in the human services field. However, the concept of people with experience of homelessness being employed in the sector was not yet accepted as common practice.

The notion of participation as consumerism and a market-based choice mechanism was one that was strongly challenged in the literature for its failure to account for the needs of the most vulnerable members of society (Barnes & Prior, 1995; Newman, Glendinning, & Hughes, 2008). Most of the service-user respondents in this
study could be considered to be among the most vulnerable members of Australian society. They were generally those who experienced disparity of participation, through factors such as illness, poverty, and experiences of domestic violence. It is interesting, therefore, that the language of consumerism continues to feature in participation activities of human services, particularly those related to mental health. Respondents in the mental health case study spoke of participation in “consumer advisory groups”, of working as “consumer advocates” and taking on roles as “consumer representatives”. While a developing movement, homelessness service-user representatives were forming into what they (and the organisations that supported them) described as “consumer advisory groups”. While they identified as “consumers” of human services, they contradicted this notion of consumerism in describing their failure to be afforded choice in accessing services. Gambrill’s (2006b) process-based approach to EBP, which was a highly individualised model of informed choice, was seen as fundamentally problematic to the service-users because in reality there were limited, or no, options from which to choose. The notion of an individualised process of EBP was far removed from the experiences of those people using mental health and homelessness services, who described having to take what was on offer, especially in times of crisis.

There was cynicism about the gap between those who could afford to pay for mental health services, and who were therefore true consumers making active decisions about their treatment, and those who could not afford to pay, who either had to take what the service system offered, refuse service and find their own means of recovery, or spend their very limited (often disability pension) income on services so that they could actually experience mental health consumerism. It was acknowledged by the respondents (service users and providers) that there were opportunities for consumerist participation in mental health services if you had the money to pay for services, but the
reflections on participation and the capacity for informed choice reinforced criticisms of 
the consumerist conceptualisation of participation. In fact, a consumerist approach 
exacerbated the disparity in participation because often-times preferred services were 
rendered unattainable to those without the means to pay, or had serious financial 
consequences for those determined to access preferred fee-for-service treatments, who 
spent disproportionate amounts of their income on those services.

While users of homelessness-related services described themselves as 
consumers, in relation to their participation as advocates and representatives, their 
descriptions of using human services indicated that they were not, in fact, consumers at 
all. Most of the respondents, at the time of interview, had been housed and had achieved 
some stability and security in their housing and income (although this was often a 
pension, casual employment or unemployment income) and were now at a point where 
they felt they had made some choice about where they lived and which services they 
accessed to support their needs. However, all respondents indicated that while homeless 
and experiencing significant crisis they were forced to take what was on offer, through 
services such as community-sector emergency and short-term accommodation facilities 
or Department of Housing, and their only choice was often between the bed on offer, or 
sleeping rough. Sometimes the bed on offer was in a location that was problematic for 
them, because it was located in an area away from social supports or where they were 
concerned about factors such as crime, or was in a facility that was governed by rules 
and regulations which they did not agree with, or which required them to compromise 
their own values and beliefs. Sometimes they did not meet criteria to receive housing, or 
were not considered a priority for housing, despite clearly identifying that they had run 
out of options for accommodation. They were not acting as consumers, and in fact were 
generally homeless because of the failure of the housing market to meet their needs.
They did not have the means, because they did not have money, a good rental history, referees, and secure employment to participate in the market-based housing sector. The inability to function as a consumer was in fact central to the notion of becoming homeless.

The value of participation was about something more than citizenship, although this was considered important, or consumerism, although this was seen as potentially powerful if one had the means to consume. Service-user participation was seen as important because without it the system of human services could not adequately meet the needs of its service users. Service-user perspectives were considered essential to fully understanding what changes needed to be made to the system. Across both case studies, there was a strong belief that the human services “need a real big shaking up” (Sue, homelessness service user). This was often an altruistic notion, whereby the service users were adamant that others should not have to endure the same negative experiences they had themselves endured. Melanie (homelessness service user), in describing her challenges for finding appropriate housing and how it had motivated her to become an advocate for others said, “it's uncomfortable [for me] getting up those stairs, but more to the point is, how many other people are really not happy and can't say anything about it?” In both case studies there was a general perception that people who had managed to successfully navigate the complex and often challenging systems of human and health services felt a responsibility to use their knowledge in a way that would improve the situation for future service users, or to speak up on behalf of others who lacked the confidence, opportunities or skills to do so. Participation was about altruism and system improvement. Even though most respondents identified significant personal benefit from the experience of participation (at an individual or representative level) and saw that it was a fundamental right, the most common and most emphasised
motivation for participation was a belief that it could lead to improvement.

Those who participated as representatives or advocates believed that their expertise and insight gleaned from the experience of homelessness or mental illness could contribute to important policy level change as to how services are funded and delivered. They did not see that policy makers and service providers could make the necessary changes to the system without that service-user expertise. Those whose participation was more personal and individualised also believed that their experience and expertise could be transformative, that it could change people’s stereotypes and assumptions regarding homelessness and mental illness, and that in individual client and practitioner interactions their active involvement would result in better outcomes. This reinforces the connection between participation and change. The act of participation was not “both the end and the means” (Beresford & Croft, 1993, p. 6) it was the means to creating change. It was not just a static human right, but an active process that was about achieving something. Service-user participation was a verb, not a noun. It is worth noting that the two service-user respondents who did not express this idea were Brian and Jack, who identified as non-participants. Brian did not participate, at a representative level, or in individual decision making around his treatment because he saw that it was pointless and that it was unlikely to change anything within his lifetime, whereas Jack saw himself as an unwilling client in the mental health system.

Strategies whereby participation was treated as an end in itself were those criticised as being tokenistic. It was when service users saw that organisations felt they had done enough just by allowing them the chance to have their say or have a seat at the table that service users felt they had not really participated. When people felt they had been asked to give input but that their input had not influenced decision making, when they had been given positions on committees but not actually been asked their opinion,
when they had been employed as an advocate but not treated as a professional, when they had been told their input was valuable but had not been paid, when they had made clear what they thought should change but nothing had changed; these were the situations where participation was seen to have failed and to have been tokenistic. The organisations may have asked service users to participate because they acknowledged that service users had a right to do so, or because there was an expectation to have service-user representation, but where that participation was not acknowledged as an agent of change it was not seen as meaningful by the service users.

The challenge for this fundamental motivation to participate, a challenge that was beyond the scope of this study to test, is that there is little evidence to indicate whether this type of participation actually creates the kind of changes to which service users aspired or whether it creates better outcomes. In this study there was not sufficient testing of the impact of participation to contribute meaningfully to such an analysis, but some indications of impact derived from service-user perceptions are available. Service users themselves had varied perceptions of the impact of their participation. Within the homelessness case study some of the participation forums were very new and had not yet had much opportunity to demonstrate impact, although respondents described that they felt their involvement in activities such as surveying and running consultations had been effective because they had quickly established good relationships with research participants to glean useful information. They also felt that their public presentations had been impactful because people had asked them questions that indicated changed thinking or had wanted to support various activities as a result of their presentation. They were pleased that there seemed to be more interest amongst policy makers and service providers in getting input from people with experience of homelessness, but there was significant cynicism about the way that this involvement was being sought,
through participation on committees and in forums. They also felt concerned about tokenism and representivity. The fact that the New South Wales Premier’s Advisory Council on Homelessness, which included two positions for people with experience of homelessness, has not functioned since the election of a new Liberal government in New South Wales in early 2011, was a source of concern for service users who claimed that the issue of homelessness was losing ground as a policy priority and that participation mechanisms had been tokenistic. Those who had participated less formally in the homelessness sector, or in one of the slightly more established advisory groups outside of New South Wales, felt positive about the impact of their involvement in one sense because they had had positive reactions when they advocated or spoke publicly on the issue of homelessness and they had had opportunities to network with people such as senior politicians. However, they were not convinced that their work had resulted in the kind of systemic change they hoped for and saw this very much as a work in progress. They had seen some changes that they felt had been, at least partly, influenced by greater service-user involvement, such as having dedicated staff to work with people experiencing homelessness at Centrelink, but were not yet sure how much the rhetoric around participation would translate into actual change.

For mental health service users, who as a group had a much longer history of service-user involvement, there were some specific examples in which respondents identified that their involvement and advocacy had contributed to systems improvement, particularly in the health system, such as changes to follow-up support processes after release from hospital and changes to medication protocols. Most respondents believed that, in speaking publicly about their homelessness or mental illness, they had effectively challenged stereotypes and stigma and had seen some shifts in the public perception of these issues, although they once again saw this as a work in progress.
How does EBP fit with these understandings of participation?

The hypothesis for this study considered EBP’s potential to enhance accountability to the people who use human services and its potential for contributing to more transparent, inclusive and informed decision-making processes. In order to examine service-user perspectives on evidence, knowledge was conceptualised, not as the domain of academics or senior managers and policy makers, but as a shared capital with capacity to be produced in collaboration with service users. The case study findings reinforced the findings from the literature review that the social sciences have not yet effectively conceptualised how to use research evidence in a way that meets the accountability for providing interventions supported by empirical evidence, while responding to and respecting the unique and complex values and needs of individuals. In fact the case studies highlight that in these areas of human service there has been a failure to effectively adopt either evidence-based or participatory practice in ways that enhance accountability, transparency and ultimately contribute to systemic change and social justice, especially within the homelessness sector, but also to a large extent in the mental health sector. The question remains then, what elements are necessary to support this type of change? If the conditions for informed decision making required from models such as Gambrill’s (2006b) individual process-oriented are not realistic and if the idealistic promises of social inclusion and EBP within policy such as the federal homelessness policy (Australian Government, 2008a) fail to be operationalised at the service level, then does this mean EBP itself is unworkable in the sector, or just that it needs to be reconceptualised? What are the elements worth holding on to in order to achieve social justice and what are the participatory mechanisms that might support such a model?
The study indicated a number of key elements related to participation and EBP that are important to service users, including:

- service-user expertise
- trusting and respectful relationships with service providers
- dynamic nature of capacity to make decisions
- desire for system improvement
- opportunity to be full member of society (employment, social, financial, and political)
- accountability for use of resources
- participation that leads to change
- payment for or valuing service-user involvement, and
- long-term and personalised nature of outcomes.

In the following chapter these elements are conceptualised within a micro (individual) approach to evidence and participation and also at the macro (representative) level, to actually operationalise a participatory model of EBP. The case studies have provided valuable insights into service-user perspectives regarding the understanding of, and exposure to EBP, the value of evidence in decision making and the types of participation strategies that are considered important and useful in achieving service-user aspirations at individual and representative levels. However, they have also indicated areas for further research, notably the impact of service-user participation and the rigour of evidence-based processes that utilise service-user expertise. The following chapter also considers these unanswered gaps and proposes areas for future research and study to strengthen notions of participatory EBP.
CHAPTER 8
Conclusions and Implications

This chapter examines how the findings from the case studies challenge and extend conceptual analyses of participation and evidence. By considering the findings in light of the propositions in the literature reviews, it explores the way in which the theoretical challenges for considering EBP within a social justice framework are reflected in the confused and often superficial interpretations of evidence and participation which feature at policy making, service use and service provision levels. While the study has revealed incompatibilities between the notions of EBP and participation, it has also demonstrated that these incompatibilities are worth reconciling because empirical evidence and service-user expertise are potentially valuable contributors to improving a flawed system of human service delivery. In considering the impact of these findings for policy making, it is concluded that neither empirical evidence nor service-user expertise can genuinely inform and improve policy unless the political nature and relative influence of each is acknowledged. Findings from the case studies consistently indicated that the knowledge and expertise gleaned from the lived experience of mental illness and homelessness is unique and important to the improvement of the human services system. This final chapter asserts that the hierarchy of evidence obstructs attempts to conceive of a meaningful role for service users in EBP and that the subjective nature of service-user expertise can potentially enrich the relevance of empirical evidence, if approached in a rigorous and transparent way. It also concludes that service-user involvement has been offered by Australian human service providers and policy makers as an insufficient substitute for participation, and that the type of
improvement envisioned by service users requires structural changes whereby providers respond and adapt to the needs, values, and preferences of users. It is determined that factors which impede access to services are important considerations for modelling participatory EBP. A fundamental step to enact a process of EBP at the level of individual service use is the building of respectful relationships with workers, a step which has hitherto been under-emphasised in models of EBP. In distilling the key conclusions from the study, the consistent challenge for implementing EBP within a social justice framework will be shown to be the application of idealistic models to the highly complex and ever-changing capacities and circumstances of service users. The implications of this subjective, complex, and dynamic approach to participatory EBP are then examined as they pertain to evidence and participation, in relation to the contribution to current conceptual debate, policy making, and practice.

Parity of participation: Means or end?

There is little consistency or depth of meaning behind the language of EBP and service-user participation which has gained popularity and featured routinely in the political sphere in Australia. Therefore, an important starting point of this study was building the theoretical knowledge of EBP and participation and interpreting it within a social justice framework. While primarily a tool for enhancing professional practice, EBP advocates emphasise its potential for increasing accountability to service users. They hold that decisions cannot be made without taking the values and interests of clients into account. This suggests an equalisation of power between the professional with expertise and the client who is the focus of intervention. Early definitions of evidence-based medicine (EBP’s precursor) highlighted the importance of a bottom-up approach, whereby the use of evidence in clinical decision making was primarily about a responsibility to the client
(or patient) (Sackett et al. 1996). This model of EBP was designed to subvert authoritarian approaches to clinical decision making. Yet, as EBP gained prominence within the social sciences and helping professions, it was critiqued for its propensity to lead to top-down decision making and its compatibility to efficiency-focused and outcomes-focused new public management (Dore, 2006). The theoretical framework for this study drew out those aspects which challenged authoritarian top-down models of decision making within social policy and human service provision and encouraged service-user participation. Accountability, transparency, and collaboration were, therefore, central to conceptualising EBP and service-user participation within a social justice framework.

Prior to this study, there was little discussion in the literature on the role of the service user in EBP beyond vague references to the clinician’s responsibility to the client (Chalmers, 1995; Myers & Thyer, 1997). While agencies like SCIE in the United Kingdom (Carr, 2006) and Campbell Collaboration (Konnerup & Sowden, 2008) had considered the role of service users in systematic reviews, there was little direct discussion of how EBP might realistically achieve the goals of accountability, transparency, and collaboration. Therefore, this study examined: (i) the opportunities available for service users in the homelessness and mental health sectors to contribute to policy and decision making; (ii) whether they were aware of, and knowledgeable about, EBP and had come across it in clinical encounters or in their consumer representative roles; and (iii) the degree of parity experienced within these encounters.

‘Social inclusion’ was a related policy discourse featuring strongly in Australian politics when this study commenced. The then Prime Minister, Kevin Rudd (2007-2010), had made homelessness a priority in his social inclusion agenda. Also an important part of policy rhetoric at the time was the notion of evidence-based policy and
service-user choice. Mental health too was firmly in the public’s mindset with media attention being drawn to serious mental illness by key public figures and the Australian of the Year Award being given to mental health advocate Dr Patrick McGorry in 2010. In the tide of these various policy priorities, a study bringing together evidence-based policy, service-user participation and choice, homelessness, and mental health was more than timeous, and Fraser’s (2000, 2005) theory of parity of participation seemed to best capture what the study aimed to achieve.

**Parity of participation**

The broad notion of participation was considered in terms of Fraser’s (2000, 2005) justice-oriented framework of participatory parity or equal access to economic, cultural, and political opportunities for all. This seemed to fit well with the goal of inclusive human service provision and social policy making, focusing on vulnerable, or “subordinated” (Fraser, 2001, p. 25) individuals and groups. Fraser (2001) drew an important distinction between recognition as a matter of cultural identity and recognition as an issue of social status. She was concerned that a growing emphasis on recognition as a matter of cultural identity had led to an identity politics surrounding issues of exclusive group identity:

Enjoining the elaboration and display of an authentic, self-affirming and self-generated collective identity, it puts moral pressure on individual members to conform to group culture. The result is often to impose a single, drastically simplified group identity, which denies the complexity of people’s lives, the multiplicity of their identifications and the cross-pulls of their various affiliations (Fraser, 2001, p. 24).
Viewing the subjects of this study through the prism of identity illuminated social constructions of ‘service users’, ‘mental health consumers’, ‘homeless persons’, and so on. For example, mental health service users in this study expressed significant concerns about the pressures for them to conform to an identity associated with mental illness, overlooking their complex identities and their diverse roles as parents, spouses, siblings, workers, friends, and members of society. Stigma and discrimination were all too easily attached to simplified identities of mentally ill or homeless people. Service users in this study were strongly motivated to participate in representative groups and advocacy activities precisely to challenge stigmatisation and discrimination and correct misperceptions. However, even the fora in which they participated as activists or consumer advocates tended to homogenise service users leading some to avoid group or representative modes of participation. Others soldiered on believing the benefits outweighed the challenges. Identity, then, was important to service users, most of whom felt misrecognised, even within the representative fora in which they participated.

To mitigate such problems, Fraser (2001) proposed a status model where the purpose was “to de-institutionalize patterns of cultural value that impede parity of participation and to replace them with patterns that foster it” (p. 25, original emphasis). Rather than focus on shared group identity, in this case homelessness or mental illness, a status model highlights the ways in which people are prevented from taking part in the full spectrum of opportunities available to members within mainstream society. In Fraser’s (2001) status model, participation involves more than representative activities and is extended to issues of access to economic, social, cultural, and political opportunities. While consumer advisory or stakeholder groups offer an opportunity for service-user involvement, they do not necessarily entail full participation in the sense in
which Fraser (2001) uses the term to refer to citizen’s achievement of full citizenship status within participatory democracies.

As indicated in Chapter 3, parity of participation marks one attempt of many to conceptualise the notion of social justice and Fraser’s notion of social justice has come under criticism for its dualism and lack of functionality as an operational principle (Honneth, 2004). Fraser (2008b) herself acknowledged the idealism inherent in her model of social justice. This study offers new insight into the potential application and operationalisation of the notion of parity of participation. It affirms the idealism of the aspirations to redistribution, recognition, and representation, indicating that actual practice is a long way from such a model. It also supports some of the criticisms put forward by Honneth (2004) because service users in this study repeatedly linked the disparity in the opportunities afforded to them to issues of identity, such as stigma and discrimination, and saw that economic and political disparities stemmed from the more general issues associated with misunderstanding them, their skills, capacities, and preferences while considered under the guise of mental health or homelessness service user.

However, in realising such weaknesses within the framework, there was also significant value in applying parity of participation within such a study (as shown in Figure 8.1). It was necessary to counter the notions of service-user involvement and the emphasis on representative modes of participation that had become dominant in Australian service-user participation discourse. While consistently linking their disparity of participation to issues of identity, service users did describe important economic and political inhibitors that tended to be overlooked in the general service-user discourse. The study reveals the value of an idealistic notion of social justice because service users demonstrated that structural change, which enhances people’s
opportunities to take part in the full spectrum of society, is actually the end goal of human service delivery, not just a tool for recognising the right to involvement. It is the aspiration (necessarily idealistic) and the mark of success. EBP, conceptualised within a social justice framework, is a contributor to this ultimate goal.

**EBP and social justice**

EBP is both a method of policy making and individual service or treatment provision. To consider EBP’s fit with notions of social justice, it was essential to explicate the priorities of the human services within such an analysis. Again Fraser’s (2000, 2005, 2008a) conceptualisation of parity of participation offered a useful starting point for drawing out what was intended by service-user involvement in evidence-based policy making. Neoliberal welfare reform reconfigured notions of service-user rights found in social justice oriented welfare discourse and replaced them with a new language of participation requirements, service-user choice, responsibilities, and obligations. It has moved from an entitlement to a mutual obligation discourse within which participation – and social inclusion – is closely associated with paid work. This narrow view of participation uses an economic language of consumer choice and human and social capital. Human service priorities within this welfare reform model shifted towards service effectiveness and efficiency, and tangible outcomes. It was one in which policies and practices based on sound research were deemed most likely to achieve cost-effective and efficient outcomes, i.e., services that worked. EBP fitted well with this new public management scenario and was readily embraced by policy makers.

Participation now became a qualified activity with narrow parameters, which aimed primarily to move people off welfare into work and looked nothing like Fraser’s status model resting on full citizenship and human rights. EBP too narrowed the
parameters of practice – whether clinical intervention or policy making – to scientifically-based interventions with proven effectiveness. The whole notion then of service-user participation seemed at odds with a contemporary reformed welfare environment extolling the value of EBP.

Service users in this study confirmed these suspicions. They elucidated ways in which their participation, as individuals or representative group members, had been impeded or constrained. For them, relevant and meaningful participation meant they were respected and able to get what they wanted as service users and advocates. Opportunities for this type of full participation were rare in the contemporary human services. With regards to EBP, most saw it as important and useful, not in and of itself, but in terms of its contribution to improving service delivery. Attention on EBP provided an important opportunity to consider what counts as evidence, and the place for evidence in shaping service-users’ decisions and of service users in shaping evidence. While respondents in this study did not necessarily consider evidence an influential consideration in their individual decision making, basing policy and practice on research was seen as important and expected. Improved access was an important hurdle to the achievement of parity of participation. Figure 8.1 shows the complementary elements of a pragmatic, flexible, modified but still rigorous and reliable version of EBP convergent with the social justice framework this study sought to develop.
Early commentators on service-user participation, such as Arnstein (1969), critiqued the notion of participation in terms of a hierarchy, whereby manipulation and consultation sat at the lower rungs and service-user control occupied the highest level. However, the conceptualisation of participation presented in Figure 8.1 considers participation in terms of a spectrum rather than a ladder, where it is a dynamic process that can be enacted at an individual or representative level. At an individual level this might relate to the way service use decisions are made and relationships with workers formed, and the ways in which the individual’s preferences and circumstances shape the options (and therefore the evidence) relevant to a ‘case’. At a representative level this posits service users as producers of knowledge that actively contribute to research processes, or as
leaders in the research process. Service users are also fundamental to the idea of accountability, with individual rights to expect effective, empirically supported practice and policy and representative capacity to demand and advocate for improved services and policy frameworks. Manipulating, informing and coercively consulting do not feature in this a parity of participation framework as they do on Arnstein’s (1969) ladder, because they are not participatory in any sense, as the service users in this study attested. Citizen control is important, as established by Arnstein (1969), but the ability, capacity and willingness to exert this control fluctuates as a service user’s circumstances change, demanding a model of participatory parity that is multifaceted and systemic. Even where a service user relinquishes decision making within such a model, where EBP is shaped by participatory principles, a service user can expect to relinquish control within a respectful, safe, compassionate and flexible context, and, importantly, to regain control.

**EBP and parity of participation: An integrated framework**

The integration of two seemingly opposing frameworks – EBP and parity of participation – in a model of evidence-informed policy and service delivery was an ambitious undertaking for several reasons. First, a great deal of misunderstanding surrounded EBP and participation and each springs from a different ideological framework. Secondly, service users described highly tokenistic experiences of participation unlikely to result in real change. Nevertheless, service-user experiences provided helpful evidence on practice, policy making, and research in the Australian human services. Thirdly, policy makers, service providers, and service users had different views on participation.
Diverse perspectives on participation

Policy perspectives

Within the case studies, key policy documents, such as The Road Home white paper and National Mental Health Plan (Australian Government, 2008, 2009), described participation as a representative process, with service-user participation through advisory committees, consumer groups, and consultation processes. Policy discourse on social inclusion referred to ways in which marginalised and excluded individuals and groups might gain full participation, but this lost currency once Kevin Rudd lost his prime-ministerial position in 2010. Within neoliberal welfare reform discourse, participation in the workforce – or economic participation – predominated.

Service providers’ perspectives

Service providers described participation in terms of service-user involvement in decision making, through inter alia formal complaint processes, consultation on issues or policies, paid consumer consultant roles, and representation on committees or advisory boards. They too emphasised representative participation which contrasted with the individual and personalised accounts put forward by service users.

Service users’ perspectives

Service-users’ understandings of participation were diverse, individualised, and complex and no one mode served their interest better than another. Representative and individual approaches to service-user involvement were seen as important. Genuine participation involved respectful engagement where service-user knowledge and expertise were acknowledged and support, resources, and payment were provided. Service users described a range of activities and strategies of participation. This
included working at a representative level as consumer consultants, members of advisory boards and committees, campaign advocates through letter writing, and conducting or taking part in research activities. However, service users also described highly personalised, individual accounts of their participation in interactions with the general public, relationships with colleagues and peers, and making decisions regarding their treatment and service use. Service users clearly expressed that their motivation for getting involved in representative fora was the hope that their involvement might lead to change in the way human services were designed and delivered. The act of participating, or more accurately ‘being involved’, was predominantly a means to this end. By concentrating on service-users’ experiences and values regarding participation, it became evident that there was a significant distinction between an individual level of involvement (about personal interactions and decision making regarding individual service use) and a representative level of involvement (about consulting or advising as a representative of the service-user perspective and advocating at a policy level).

These divergent perspectives demonstrated a lack of common understanding about participation. In the absence of empirical evidence on effectiveness of particular modes of participation in particular situations, little guidance on productive participation could be found. Hence Fraser’s (2001) parity of participation framework provided a useful theoretical model for service-user involvement to fill this gap.

**Evidence and participation in policy making: Intrinsically political influences**

The study sought to explore whether evidence-based practice and policy making valued service-user representation by examining the extent to which service users were engaged in contemporary policy making. Formal representative participation
mechanisms were well established in the mental health sector but only developing within the homelessness sector. There were formal processes for users of mental health services to contribute to policy making, largely through state and federal consumer advisory groups funded through state and federal health departments. For some, this was a promising development and an appropriate participatory mechanism. However, for others this formal channel made them feel more excluded, because they did not have the interest, confidence, skills, or technological access necessary to take part. In contrast, homelessness service users had only recently been granted formal channels for contributing to policy making, through consultation fora and service-user representation on the Premier’s Advisory Council on Homelessness in New South Wales. There was little evidence of formal participation in federal-level policy making.

Evidence-based policy making and participation were treated largely as two separate concepts in homelessness and mental health policy. Evidence-based policy making was enacted through key bodies of research (often commissioned by the government) informing a policy-making process. In relation to Weiss’s (1979) seven types of relationship between knowledge and policy making, the Australian government’s move towards EBP was premised on a problem-solving model, whereby research was used to help address specific policy problems. This was certainly the case in homelessness policy approaches, where research had been commissioned to assess the effectiveness of various models and interventions to “halve overall homelessness by 2020” and “offer accommodation to all rough sleepers who need it by 2020” (Australian Government, 2008, p. 17). The underlying principle for evidence-based policy making pertained to political problem-solving, whereas the impetus for inclusive participation strategies was about recognition of people’s right to participate. It had resulted from pressure from lobby groups and mental health advocates. Interestingly, however, this
led to significant criticism from service users about tokenism, largely because they wanted to be involved in problem solving. The case studies suggested that, for government, the input of service users was a less direct and obvious influence on policy than evidence. Furthermore, the participation of service users on expert panels, such as national advisory bodies, was limited (and often non-existent). Their membership usually comprised expert academics and service providers, who acted as spokespeople on issues of homelessness and mental health. At a state level, the participation of service users in policy advisory capacities was more evident, but still quite limited.

It was difficult to envisage an integrated model of evidence-based policy making and service-user participation given current approaches and perspectives. However, one key area in which the two policy influences might be compatible is the generation and dissemination of evidence. Service users interested in representative activity certainly saw roles for themselves in research. While the contribution of service users to the generation of evidence is discussed below, it is important to note at the outset the way in which service-user participation and evidence-based policy making might converge.

In exploring the usefulness of evidence in informing service-user representatives’ advocacy and lobbying agendas, the incompatibility of social justice goals and scientific objectives was revealed, because most service users were not interested in objective approaches to representation. Their very involvement was subjective and personal and motivated by hope of changing a flawed service system. Service users who had taken part in advisory and representative groups said surveys and peer consultation, formal and informal, were important means for establishing key issues for their representative activities. Many referred to the information collected through surveys and consultations as evidence and, therefore, saw their approach as evidence-based. More methodologically rigorous approaches could be categorised as
research. However, none of the strategies described in this study would feature in the hierarchy of evidence. Hence representative service-user involvement, and empirical evidence to ground EBP, derived from fundamentally different ideological positions. Service-user representation sought to provide subjective insight derived from experience to infuse policy making with personal, realistic accounts, so as to ensure that policy was appropriate, responsive, and effective in solving the problems it was designed to deal with. Government attempts to ground policy making in an objective, scientific approach led to highly complex, politicised issues. Evidence is far from neutral:

There is a risk that ‘evidence-based policy’ will become a means for policy elites [to] increase their strategic control over what constitutes knowledge about social problems in a way that devalues tacit forms of knowledge, practice based wisdom, professional judgement, and the voices of ordinary citizens (Marston & Watts, 2003, p. 158).

The implication is that evidence-based policy making should consider the role of service users, professionals, and the general public in policy decisions. This was highlighted in the homelessness case study, where it was difficult to determine the interplay between expert advisory panels and evidence gleaned through commissioned research and broad consultation. In failing to recognise the various factors that compete with evidence to influence the policy process, the notion of evidence-based policy making seems disingenuous.

The divergent influences of evidence and service-user involvement on policy making need not necessarily be at odds. It seems tautologous to suggest that policy making is political, but attempts at evidence-based policy making have attempted to
mask the intrinsically political nature of the process. An honest account of the policy-making process would acknowledge these various pressures and influences and consider the way in which evidence and service-user involvement might be used to inform and guide the process. In an address on the nature of scientific evidence and values, former Chief Scientist for Australia Penny Sackett (2011) appealed for an honest and open discussion of “assumptions on which the evidence rests and the values we use to judge our actions” (unpaginated), highlighting that the evidence resulting from scientific research needs to be considered against, and not confused with, the moral and ethical values of society, which form the backdrop to social policy and service delivery. Within a social justice framework, cognisance must be taken of the ideas, interests, and opinions of the people whom the policy is likely to affect. Hence service users should be involved in the policy-making process.

**Service-user expertise and empirical evidence: A pragmatic approach**

The notion that some types of knowledge were more reliable than others was fundamental to the evidence hierarchy. However, one of the key findings of the literature review (Chapter 3) was that explicit and scientific conceptions of evidence had been problematic for the uptake of EBP in the social sciences. This study confirmed the problematic nature of narrow views of evidence, given the complex needs and personal circumstances of mental health and homeless service users. As already noted, the concept of evidence was poorly understood and there was little consensus on what constituted evidence. Social workers tended to take a broad view of evidence (Gray et al., 2009) and, like the service users in this study, considered knowledge derived from lived experience – in this case of mental illness or homelessness – as equally important
to research-based knowledge derived from rigorous systematic reviews and randomised controlled trials (Boruch, 2008; Roberts & Yeager, 2004). Pawson et al. (2003) identified user and carer knowledge as a distinct category of knowledge within social care. They suggested that the standard for measuring high quality user and carer knowledge ought to be its demonstration of “accountability”, “use of a social model”, “clarity of ideological standpoint” and “empowerment” potential (p. 62). Social work also valued qualitative research (Denzin, 2009) and critical realism (Pawson, 2006) which took into account the complexities of human experience and politicisation of evidence (Buetow & Kenealy, 2000; Daly, et al., 2007; Glasby & Beresford, 2006). These issues aside, debates on the nature and definition of evidence made little difference to service users in this study who drew on a wide range of information from diverse sources. For them, the knowledge gleaned from their experience as service users and consumer consultants constituted evidence.

Respondents were positive about improving accountability, particularly to those who used services. For example, Paul (homelessness service user) described the way in which greater reliance on research to inform practice might hold agencies accountable for the way in which services were delivered and correct the attitude that service providers or professionals “know what’s best for them [the service users]”. There was thus some endorsement of EBP as research-informed practice, but professional expertise had to be balanced by service-user expertise. Certainly it was difficult to argue against practice and policy making based on in-depth analysis of an array of information sources if the alternative was arbitrary decisions based on organisational priorities and preferences.

A small group of service users in this study understood EBP and the hierarchy of evidence. They expressed concern about EBP’s applicability to human services, because
they were wary of the way in which quantitative research methods were privileged and other sources of evidence overlooked, notably service-user experience and expertise. Even among those with a more sophisticated understanding, there was a tendency to talk about evidence-based practices rather than a process of client-worker engagement. Some mental health service users in this study saw evidence-based practices as problematic because they did not reflect their unique values, circumstances, and preferences. This was not an issue in the homelessness case study because the types of practices or models seen to be evidence based tended to be in line with policies which service users thought would work well, such as housing first. Essentially, though, it was not significant whether a service user viewed EBP positively or negatively as this was largely an issue of semantics. Some thought evidence was broad and all-encompassing and, therefore, saw a place for their expertise and insight, while others saw it as narrow and restrictive and biased towards certain types of knowledge (and modes of practice, such as the medical model).

It can be concluded that, for the most part, EBP did not translate to meaningful service-user involvement in mental health and homelessness practice or policy making. Instead it has led to use of the term as a buzzword or jargon which is indistinguishable from prior incantations of ‘best practice’. In short, evidence was meaningless to service users, and to some service providers, where it did not reconcile with the contribution of service-user expertise. Overwhelmingly, service users sought information and guidance from other service users because they trusted and connected with them and shared ideas, experiences, and opinions – expertise. Glasby and Beresford’s (2006) model of knowledge-based practice rested on the relationship between empirically-derived and personal knowledge derived from experience. For them, service-users’ involvement in research was essential to overcome the barriers between researchers and subjects and
ensure sound, relevant, and ethical research. For them, and the participants in this study, service-user expertise must be accommodated in an integrated model of EBP that allows for recognition, redistribution, and representation (see Figure 8.1). There is a sense in which the roles service users might play in generating and contributing to research evidence – a representative type of activity aimed at shaping and influencing service provision (see Table 3.1, Chapter 3) – might be seen as recognition of service-user expertise and redistribution of power in the service user-provider relationship. In this integrated model, the service-user’s insight, knowledge, values, and expertise determines judgements about relevant evidence. The onus is not on service users to behave like consumers shopping around for services or advocates championing their own interests, but on service providers to understand the service user and mould services to fit the circumstances of a client. This model supports service users in seeking information independently (such as through the internet), but does not demand this of service users. Such a model emphasises that the skill required of practitioners and professional service providers is to engage with and understand the needs of service users, critically assess what is relevant and meaningful evidence to a particular circumstance, and then apply this with a level of collaboration appropriate to the capacity of the client at the time.

The process of EBP includes the relationship between service-user and practitioner expertise and research evidence (Gambrill, 2010; Thyer & Myers, 2011) and this process can and, according to Sackett et al.’s (1996, 2000) original definition, does account for the service-user’s values, preferences, and interests. Figure 8.2 highlights the service-user’s perspective as the frame for the appraisal of evidence, or within which the process of EBP takes place. In this model, the service-user’s insight, knowledge, values – their expertise – is the lens by which other types of knowledge are
either included or excluded. It suggests that before a judgement can be made about the research evidence applicable to a particular circumstance, there is an impetus to understand the service-user’s preferences, history, values, aspirations, and environment in which they live in order to ascertain what is relevant and important for the specific situation. Given that capacity issues may exist, whereby it is not possible for a service user to express these ideas at certain times (and often this may be at the beginning of their service-use journey when they are at their most vulnerable and critical), this information may be gleaned over time, requiring constant re-evaluation of the evidence or through mechanisms such as Ulysses Planning (described in Chapter 6) or using existing records and information (requiring confidentiality and information-sharing protocols across agencies). This type of model, while useful as a heuristic device, oversimplifies what are complex and dynamic circumstances. However, it demonstrates a shift in emphasis, whereby the service-user’s expertise is not a component of EBP, to be weighed and measured against professional wisdom and research evidence, but shapes the way in which other types of knowledge are applied to a situation.

**Figure 8.2: Service-user expertise as knowledge frame**

![Service-user expertise as knowledge frame diagram](image-url)
What is less clear, however, is what counts as evidence and the relationship between service-user expertise and evidence. Is the service-user’s role limited to the broad domain of individual expertise shaping the process of EBP within individual interactions, or do service users have a legitimate and valuable role in contributing to research evidence (and also potentially to practitioner expertise given that, in the mental health sector some consumers are employed professionals)?

In relation to the representative role of the service user, his or her expertise would be considered in relation to the evidence hierarchy, as a contribution to the evidence base. While not all versions of the hierarchy of evidence include service-user opinion on the lowest rung, as part of expert opinion, some do (Fraser et al., 2009; Glasby & Beresford, 2006). It is a somewhat incongruous inclusion on the hierarchy that a tool designed specifically to reduce bias and introduce rigour and accuracy to practice and policy decision making would include the highly subjective category of expert opinion. Rather, proponents of EBP seem to suggest that the value of expert opinion is in critiquing, analysing, and reviewing the evidence as derived from, not contributing to, the hierarchy. There are a number of problems in positioning expert opinion on the lowest rung. One is that, as a hierarchy, this implies that the opinion of experts, including service users, is less reliable and less useful in formulating social service programs and policy, an implication which feeds into criticism of EBP as overly authoritarian, simplistic, and lacking in understanding of the importance of professional judgement (Denzin, 2009; Dore, 2006; Hammersley, 2005). Secondly, it fails to capture the way in which service-user perspectives (and the perspectives of other experts) might contribute to the formulation of different types of evidence and that service users could have a role in leading, participating in, and informing methodologically rigorous
research, a role which the respondents in this study considered to be important to their functions as service-user representatives. Fraser et al. (2009) and Glasby and Beresford’s (2006) inclusion of expert and consumer opinion within the hierarchy of evidence fails to recognise the distinction between the scientific process of ranking evidence according to likely impact of bias, and the process of implementing and applying evidence for practice, which takes service-users’ preferences, values and circumstances into account as a starting point, and is undertaken with due professional wisdom, as shown in Figure 8.2 and recognised by Haynes, et al. (2002). Services users may play quite distinct roles in EBP, as the individual service user, whose preferences, values and circumstances shape the process of applying evidence, and as representatives of service users involved in conducting or contributing to research and therefore generating the evidence base. Neither of these roles requires service-user opinion to feature within the hierarchy of evidence, and in fact, it is confusing to do so. Nevertheless, what these roles suggest, is that the current scientific process for assessing and ranking evidence according to likelihood of bias, tends to work against inclusion of research which involves service users, because the methodologies employed in many examples of service-user research sit outside this hierarchy.

Plath (2008) suggested four distinct theoretical influences on EBP within the field of social work: positivism, pragmatism, politics, and postmodernism. The diversity of these theoretical influences and the contradictions inherent in such disparate influences played out in this study. Much of the literature on EBP as a model derived from evidence-based medicine, where the hierarchy of evidence was central, tended towards positivism. Supporters saw the application of an evidence hierarchy as a way to reduce bias, improve reliability, and meet accountabilities for delivering effective services (Chalmers, 2005; Gambrill, 2010; Oakley, 2006; Thyer, 2008). Critics
suggested that positivistic approaches failed to account for complexities and realities of social sciences and did not sufficiently consider the benefit of qualitative methodologies (Denzin, 2009; Hammersley, 2005). The positivistic approach to decision making that distinguishes EBP from other approaches, such as ‘best practice’ and ‘good practice’. The positivistic model of EBP presents a dilemma for participatory practice viewed from a service-user perspective within a social justice framework. Service users in this study clearly indicated that they responded to and respected information which came from fellow service users which was unlikely to meet criteria for inclusion as evidence within a positivistic discourse. Despite this, initiatives such as recently funded controlled studies on the impact of service-user participation in health programs in Victoria mark early attempts to reconcile the value of service-user input with the hierarchy of evidence (Thomacos & Roussy, 2011). Those service users with the interest and capacity to participate in representative activities also clearly indicated that they considered contributing to and, in some cases, leading research as an important and relevant component of their role as service-user representatives. However, the interest in research was not objective. For example, Greta (mental health service user) engaged in a participatory action, user-led study on peer support for the explicit purpose of demonstrating that this type of intervention was effective within a recovery framework, in order to advocate for greater funding for this type of activity. The outcome sought from the study was predetermined and the bias was significant. The evidence was politicised in this instance, to be “used strategically to obtain resources, further causes” (Gray et al., 2009, p. 53), in opposition to the positivistic approach to EBP. Similarly, most service users in the study indicated that their interest in acting as representatives and advocates was premised on a desire for change and improvement and they had formulated specific ideas about what this would look like. Far from objective
approaches to evidence generation, they saw that their subjective knowledge derived from personal experience was important. As such, this study has indicated that, while academic debate on EBP has centred on the positivistic framework, service users perceive themselves to have a role in EBP that fits within a political framework, indicating again the tension between a scientific and social justice approach to practice and policy making.

Within the discourse of pragmatism, various authors have attempted to redefine EBP in such a way that it accounts for diverse modes of knowledge drawn from qualitative and quantitative research, as well as professional and service-user perspectives (Buetow & Kenealy, 2000; Glasby & Beresford, 2006; Pollio, 2006). The pragmatic conceptualisation of evidence, whereby evidence is considered to be useful, relevant, and available in a specific situation also seems the most common interpretation adopted by policy makers and practitioners, as demonstrated in the responses of social workers to the survey conducted by the Research Institute of Social Inclusion and Wellbeing. This pragmatic approach marks a middle ground between the politicised notion of evidence from a service-user perspective and the positivist notion of evidence according to researchers and academics.

Positivistic conceptualisations of EBP do not recognise service-user expertise as a type of evidence because of the subjectivity and bias implicit in, and important to, this type of knowledge. However, as shown in Figure 8.2, at an individual treatment level, the service-users’ interests are central to the critical appraisal of research evidence. Positivistic EBP is also at odds with the idea of service users as researchers, because service-users’ subjective experience is not a valid form of knowledge despite the fact that service-user involvement might make research more relevant, applicable, and meaningful. The inclusion of service users in systematic reviewing processes might bias
outcomes and, indeed, as indicated in this study, that would be service users’ intention with social justice and service improvement as a goal.

Hence EBP and participatory parity are at odds with one another. It is important, however, to note that the very idea of a positivistic notion of EBP was challenged within this study. Evidence was not understood in this way by most of the people who used and provided services and those who had an understanding of the hierarchy of evidence were sceptical about the objectivity of systematic reviews and randomised controlled trials. They saw these methods as biased towards agents with the resources, interests, and capacities to conduct research of this nature.

Service users could have a role in contributing to the evidence base where EBP was conceptualised as pragmatic, acknowledging the challenges to objectivity, while still using systematic, rigorous methods and a wider range of research approaches and contributions. This was apparent in Fraser et al.’s (2009) inverted hierarchy of evidence for intervention research, whereby consultation with experts, including service users, was placed on the first rung of the hierarchy, working upwards towards randomised controlled trials as the final stage in testing. Glasby and Beresford’s (2006) proposition of knowledge-based practice and Pawson’s (2006) realist synthesis are similarly representative models which acknowledge rigorous and reliable research to inform decision making while not ignoring complexities and context. Similarly, attempts at conceptualising how qualitative research methodologies fit within, or alongside the hierarchy of evidence (Cochrane Collaboration, 2002; Daly et al., 2007), indicate pragmatic views of EBP which recognise the significant promise of accountable and effective service delivery. While the hierarchy of evidence may in fact contribute to disparity and subordination by devaluing subjective forms of knowledge and expertise, the entire notion of EBP should not be disregarded:
We agree that we should adopt an inclusive view of evidence, and that professionals need to be prepared to critically assess evidence using appropriate criteria. We expect the evidence challenge to be dynamic, and that it will always be present. As values, methodologies, and ethics evolve, so too will judgments about what should be considered as evidence (Mullen et al., 2005, p. 72).

The challenge, therefore, for ongoing research is to devise tools to support the critical appraisal of evidence while acknowledging the complex realities of human services practice, bearing in mind that rigour and reliability need not necessarily exclude service-user contributions. In the absence of evidence on the most effective, fair, and inclusive means of engaging service users in research, service users in this study valued the knowledge and wisdom gained from their peers (Faulkner & Thomas, 2002; Nilsen et al., 2006; Oliver et al., 2004). Notions of participation are complex and require dynamic and flexible approaches to service-user engagement. Service users are mindful of the way in which they have been offered tokenistic opportunities to participate that have been about placation more than participation. Engaging in research might offer a means for redressing imbalances in power between service users, policy makers, and service providers, because it is a means by which expertise might be explicitly acknowledged and by which knowledge might be considered collaborative (as shown in Figure 8.1).

**Engagement with services and workers: The crucial first step**

At the interface between service user and provider, client and clinician, participation is implicit in the idea that in considering the evidence, professionals must take account of client values and interests so that the ultimate decision about treatment or intervention – or service use more broadly – is the client’s. This is bolstered by the neoliberal discourse of client choice, which implies that clients have a range of service options
from which to choose. They can shop around for services. However, services are usually limited and access is often problematic for clients, especially in the homelessness sector, where there are acute accommodation shortages.

While evidence-based policy making concerns macro solutions and undergirds service provision at the national, state, or territory and regional levels, EBP as a clinical process involves a different approach. One of the challenges to EBP in the Australian human services is the lack of understanding of this collaborative and individualised process (Gambrill, 2006b). This study and the survey of social workers for the project Implementing Evidence-Based Practice: Factors that Influence the Use of Research Evidence by Human Service Professionals have demonstrated the confusion among service providers and users surrounding EBP variously perceived as research-based practices, treatments, or interventions with proven effectiveness. The collaborative, individualised, and process-oriented approach to EBP envisaged by Sackett et al. (1996) and Gambrill (2006b) rests on a five-step process in which the problem is defined, and practitioner expertise and client values determine decisions about treatment. This collaborative, accountable, and transparent model is quite compatible with principles of service-user participation in which service users engage in effective relationships and open communication with service providers. However, the service users in this study identified a number of problems regarding open communication, such as a reluctance to share accurate information about their circumstances or health due to fear of repercussions like hospitalisation for the mentally ill or exclusion from accommodation services for those threatened with homelessness. Because of power imbalances in the user-provider relationship, it was often not in the client’s best interests to engage in honest communication. Providers facilitated access to much-needed services and clients had to ‘play the game’ to get their needs met. Examples from this study included:
mental health service user Greta telling the Mental Health Review Tribunal she was complying with the medication regime and only revealing that she had not, in fact, been taking the medication after the treatment order expired; mental health service user Jack not telling workers about his actual thoughts and beliefs because he knew they would be considered delusional and might result in hospitalisation or changes in medication; and Jasmine’s dilemma about her relationship with another resident in a medium-term accommodation facility knowing that this was not allowed and would result in certain eviction. Thus establishing strong, trusting relationships with human service workers or mental health professionals is a tricky business. The open communication pivotal to EBP is difficult to achieve when resources are limited and highly conditional. The same dynamics are likely operational in service-user participation’s undue emphasis on group identity and representative modes of participation.

As shown in Figure 8.3, respondents in this study described experiences of service use as driven largely by the accessibility and availability of services, with ample points at which they were likely to disengage from the process, such as not meeting selection criteria or failing to develop good relationships with human service workers (which might result in expulsion or self-removal from a service). EBP was seen to feature only in relation to the actual intervention provided, if at all, though most service users assumed or expected that the intervention they were offered would be based on sound knowledge and proven effectiveness (i.e., they presumed that research or past experience had shown that it worked).
Figure 8.3: Typical service-use journey (existing)
However, some service users, particularly in the homelessness sector, were sceptical about the extent to which interventions were based on proven effectiveness. Some, particularly in the mental health case study, regarded this as a positive and trusted the professional expertise of practitioners. However, this was problematic for Tara who wanted to access alternative treatments and therapies without evidence of effectiveness. The evidence or, more likely, information regarding effectiveness (which might combine research and practice wisdom) was seen as very much in the control and domain of the professional. Service users did not routinely go in search of evidence or information about treatments. Further, intervention or treatment choices depended on the client’s willingness to accept what was on offer and conform to existing treatment regimes. There was little flexibility to adapt to service-user’s needs or preferences. Service users said the only power they exerted was in accepting or declining services. Declining services could mean sleeping rough or hospitalisation. Their choices, however, were limited and, for the most part, considerations of whether or not interventions were evidence based hardly mattered to them. They tended to accept what was on offer and remained positive about services where they had established a good relationship with welfare workers or health professionals. This one-size-fits-all model is out of step with bottom-up EBP that supposedly “begins and ends with the … clients’ unique experience with their presenting problems” (Shlonsky & Gibbs, 2006, pp. 103-104). Privileging research evidence was seen to contradict a client-centred approach. Figure 8.4 reconceptualises the journey of service use with consideration to ways in which evidence and participation might alter the journey, in light of the recommendations and perspectives of service users from this study. It demonstrates how EBP as an individualised process might affect the service-use journey, and also considers the central importance of the relationship between the worker and the client.
Figure 8.4: Integrated participatory EBP service-use journey

Individual requires support (e.g., at-risk of or experiencing homelessness, poor mental health)

Formal (from agency) or informal (word of mouth) referral or recommendation to service

Builds relationship with worker/s (to understand client experiences, presenting problems and outcomes sought)

Worker collates evidence and options and presents to client

Client and worker discuss preferences and availability of resources and select intervention/s

Intervention/s

Follow-up and assessment of outcomes for client

Revise case plan and readjust accordingly
Both *The Road Home* white paper (Australian Government, 2008) and the *National Mental Health Plan* (Australian Government, 2009) established the importance of a ‘no wrong door policy’ meaning that service users were guaranteed a connection to a service, either through expansion of an existing service, i.e., increasing the options available, or referral to a more appropriate service with follow up (Croton, 2006). Within the integrated framework shown in Figure 8.4, services would adapt and respond to a client’s needs, using evidence-informed decision making, rather than bouncing the client between services, as was the experience of homelessness service users in this study.

This collaborative, process-oriented EBP approach cannot work without a range of service options and interventions with proven effectiveness from which to choose. However, service users in this study made it clear that, for them, there was often very little choice involved in their experience of services. Even with federal and state policy emphasising a greater reliance on evidence to inform resource allocation and an emphasis on the no wrong door policy, service options were extremely limited. Bureaucratic processes too inhibited choice by assessing clients in terms of benefit categories. This did not apply, however, to private mental health services for those who could afford them. Managed care, while it allowed some choice, was also problematic for participatory EBP. Further, in times of crisis, service users might not be capable or want to make treatment decisions. The respondents in this study indicated that money was not the only restriction on choice of service. Transport, geographical location (urban, regional, and rural), and fit with a service (which often meant whether they identified with the service’s other users) were also important. Barnes and Prior (1995) suggested that the neoliberal tendency towards treating service users as consumers and
prioritising individual choice could lead to stress, confusion, and further marginalisation. Hence a better approach was to provide the means for service users to influence and shape the content of services. In relation to this study, it emphasised that advocacy needs to happen at a policy level and that service users need to be part of evidence-based policy making. At an individual level, however, agencies need to facilitate and guide access to appropriate services and ensure engagement with workers as a fundamental component of participatory and evidence-based practices.

**Complexity demands flexibility**

Frameworks are, by their very nature, reductionist and overly simplistic and the reality of EBP implementation and participatory parity is far more complicated than Fraser (2000), Gambrill (2006b), and others’ modelling suggests. The complex and dynamic circumstances of service-users’ lives and of decision making were accentuated repeatedly throughout this study, with individual respondents indicating the importance of recognising the heterogeneity of service users and the ways in which individual service users’ circumstances, capacities, preferences, and values might change over time. The dynamic, complex, and diverse ways in which service users engage with human services are defining features of the sector, which have not been adequately considered in EBP and service-user involvement strategies. Service users were sceptical of and frustrated by “one-size fits all” models (Jane, homelessness service user; Greta, mental health service user; Brenda, mental health service provider) or “cookie-cutter” (Penny, homelessness service user) approaches to practice and policy making that did not account for the heterogeneity of service users or their ever-changing circumstances. It was a fundamental concern about EBP, more so because it was interpreted as evidence-based practices rather than as a process, that it would reinforce one-size-fits-
all approaches and limit options for accessing services and interventions which might not have research backing. Interestingly, service-user involvement strategies were also perceived as inflexible, requiring service users to adapt to and fit within particular types of activities, rather than demonstrating the type of structural change to break down barriers to participation envisaged by a parity of participation framework. While at a policy level much was made of notions of social inclusion in the homelessness sector or recovery and client-centredness in the mental health sector, the implementation of policies pertaining to EBP and participation did not seem to account for the diversity and complexity implicit in such ideas, rendering them meaningless, tokenistic, and jargonistic.

The process of EBP is about informed and collaborative decision making, which seems like a reasonable premise, except that it implies a degree of rational decision making that may not exist in many situations in which human services are delivered (Luitgaarden, 2007). The notion of EBP as a collaborative and transparent process suggests that the service user or client is a willing, rational, and functional participant in the decision-making process. The study found this to be a flawed premise on which to establish a model of practice and policy making because, as described by the service users in these case studies, the actual circumstances in which decisions were made were often critical, volatile, and desperate and service users might be, at points in the journey of service use, unwilling or unable to engage in a collaborative process of decision making. Mental health service users described times when they were experiencing severe episodes of illness, such as psychosis, when their capacity and willingness to make decisions was severely impaired and they relied on professionals to make good decisions on their behalf at such times. However, as people became well and learned more about their illness and their own preferences for treatment and intervention, they
tended to want to engage in collaborative modes of decision making and request information to support informed decision making. This again demonstrates the vital nature of the relationship between workers and service users as a preliminary step in the service-use journey (see Figure 8.4), because the essential skill of the professional, under-recognised in existing models of EBP, is to be able to ascertain and adapt to the changing capacities and circumstances of the client. While the dynamic nature of decision-making capacity was clearly emphasised by service users in the mental health case study in relation to episodes of illness, in the homelessness case study it was expressed in relation to the vulnerability and desperation experienced at different stages of homelessness. Many of the homelessness service users said there were times when their lives were so stressful and their need was so great, that they would have felt overwhelmed by receiving large amounts of information and just wanted quick access to good housing options. Some had also experienced severe mental illness or drug or alcohol dependence that impaired their decision-making capacity at certain points.

Across both case studies, service users expected and needed to be engaged in the decision-making process, though this varied and was subject to change at any point. As such, in considering service-user expertise as the lens through which evidence and professional wisdom was filtered (as per Figure 8.2), it became apparent that this was a dynamic process requiring constant re-evaluation of the service-user’s circumstances and capacity, ongoing reappraisal of the evidence and constant adaptation of the manner and extent to which evidence was shared with service users.

The dynamic nature of people’s capacities and interests also significantly impacted on the way in which they engaged in formal participation structures. Both case studies demonstrated that people were more likely to take part in formal activities when their circumstances were relatively stable. A commonly cited reason for this was that,
when experiencing crisis, it was vital to concentrate on the task at hand. However, it was not just about the individual’s capacity or willingness to participate, but also the way in which participation had been construed as particular sets of activities, such as taking part in fora or committees, that were really only accessible to those with resources and capacity (including stability) to take part. Cruikshank’s (1999) assertion that participation and empowerment were, paradoxically, tools to enact compliance and make people govern themselves through “the capacity of citizens to act upon themselves, guided by the expertise of the social sciences and social service professionals” (p. 89) was a concern reflected in this study, because the tools of participation were controlled by the authorities (such as government and service providers) rather than service users themselves and were overly simplistic, homogenous responses to highly complex and dynamic circumstances. In fact, there was some cynicism about whether participatory practices were deliberately exclusionary because policy makers and practitioners were seen to be ill-prepared to confront and accommodate service users who were in the midst of crisis. This was in stark contrast to Fraser’s (2000) notion of participatory parity, which emphasised the structural nature of participation, in which the opposite would hold true, because participatory parity would be realised where the most vulnerable and subordinated members of the society had opportunities to take part in economic, political, and cultural activities.

Importantly, this study revealed that participation was not just about representative and formal notions of participation emphasised within policy frameworks and practice settings, such as advisory groups, committees, and consultations, but also involved a plethora of ways in which people sought to gain power, respect, financial security, and recognition. Table 7.2 (Chapter 7) summarised the complex ways in which service-users’ participation was impeded. Table 8.1 summarises some of the responses
that service users themselves identified as participatory mechanisms, demonstrating that their conception of participation was much more rich, dynamic, and heterogeneous than that conceptualised in policy frameworks in Australian human services.

Table 8.1: Diverse modes of participation

<table>
<thead>
<tr>
<th>Economic</th>
<th>Cultural</th>
<th>Political</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use income to purchase private services</td>
<td>Challenge stereotypes by presenting in public and personal exchanges as intelligent, kind and ‘normal’</td>
<td>Take part in formal advisory groups and committees</td>
</tr>
<tr>
<td>Retrain and educate to access different job opportunities</td>
<td>Gain education</td>
<td>Speak publicly about experiences as a representative</td>
</tr>
<tr>
<td>Learn about the social benefits system in order to access maximum payable benefit</td>
<td>Access those services where one felt respected</td>
<td>Set up service-user run groups, activities and research projects</td>
</tr>
<tr>
<td>Work as a paid consumer consultant</td>
<td>Build positive relationships with workers</td>
<td>Take part in letter-writing campaigns</td>
</tr>
<tr>
<td></td>
<td>Be a ‘whole’ person (not just about illness/issue) – build relationships, work, have diverse social and recreational interests</td>
<td>Advocate as part of a formal group or as an individual for friends, peers and family</td>
</tr>
</tbody>
</table>

Again, the importance of considering the dynamic, complex, and heterogeneous circumstances and capacities of service users is essential to understanding the ways in which policy and practice might more effectively deliver accountable services that achieve positive change. The thinly conceptualised notion of participation as a representative seat at the table has resulted in service users lamenting the tokenism of participatory practices. Many disengaged from formal participation activities because they did not feel they had the skills or resources to take part or because they felt their unique and manifold identities would not be respected. In this sense, the notion of parity
of participation is a useful device because it considers participation as the way in which society (and its agents, in this case, the human services) supported individuals’ access and opportunities to take part in and reshape the structure of society. It is concluded that, in order to achieve such enhanced opportunities for marginalised service users, the one-size-fits-all approach to participation evident in this study was insufficient. Service-user participation is about the ways in which people access, use and engage with services, but is also about the ways in which service users access broader opportunities within a society as a result of an intervention. Again, participation is a process but also, importantly, the goal for successful human service interventions.

An impetus for this study to reframe EBP from a service-user perspective, in keeping with principles of social justice, was the difficulty for existing practice and policy approaches within the human services to grapple with the concept of outcomes. The emergence of new public management and neoliberalism saw an emphasis on outcomes-based management, but, within this discourse, an outcome was a managerial tool pertaining to efficiency and resource use. For the human service sector, this failed to adequately describe the way in which the person who used a service might conceive of a successful outcome. In exploring the potential of a bottom-up model of EBP (as envisaged by its early advocates), whereby the outcomes for an intervention were individualised and personalised, this study construed EBP as a process in terms of which the service-user’s priorities, preferences, and values shaped the way in which the evidence was appraised and informed the goals for the intervention (see Figure 8.2).

In an ideal collaborative, transparent, and accountable mode of practice this would function in such a way that the service provider and service user would come to a shared understanding regarding the outcomes sought, the service provider would appraise the evidence to determine a range of options pertinent to achieving those
outcomes, and the service provider and service user would together agree on the preferred option/s based on the available evidence. This study highlights that the reality of service use for people with mental illness or experiencing homelessness is complex and dynamic and, as such, the determination of outcomes as proposed in the ideal model is actually highly problematic. Hope (2002) asserted that understanding the service-user’s values and preferred outcomes was essential to evidence-based approaches and determining whether an intervention had been successful. The notion that service users ought to have a role in determining outcomes was also central to concepts like recovery within the mental health sector, whereby the concept of success was highly personalised and individualised. As such, a process-oriented, bottom-up approach to EBP was seen as being potentially compatible and useful to working within a recovery framework (Davidson et al., 2009).

While service users in this study were generally adamant about their capacity to determine the outcomes they sought when using human services and considered this an essential part of their expertise that would need to be factored into a model of EBP, they were also mindful that, at some points in their lives, they would not have had the capacity to identify or articulate the outcomes they sought. Within the mental health case study, many of the service users noted that what it meant to ‘be well’ was not a fixed concept, but was a notion that had evolved and continued to change over time. Within the homelessness case study, notions of successful outcomes also evolved and changed, as people’s expectations and circumstances changed and as they moved between periods of crisis and stability. There is, therefore, a problem in individualising human service use to the point at which service users must be able to identify and articulate outcomes in order to have a meaningful and successful intervention, or in placing too much responsibility on the service user for the success or otherwise of an
intervention. Again, this may be where a richer notion of participation, in accordance with the participatory parity framework, is useful. Where participation in service use is narrowly defined as the individual service user contributing to, or determining, preferences for outcomes and interventions, there is not sufficient breadth to incorporate participatory principles in situations where an individual’s capacity is limited. In this case, participation becomes a privilege that is only earned when a certain point of stability is attained and which is withdrawn when that stability falters. However, where participation is considered in relation to the structural enablers and inhibitors that allow a person to access the full range of opportunities within a society, the complex and dynamic nature of people’s capacity can be accommodated. The notion of participation becomes a guiding principle by which interactions with service users can be measured and the test by which policy makers and practitioners examine their work is the extent to which it either enables or inhibits participation, based on current circumstances of an individual (or group of individuals for policy makers).

That people’s values, priorities, capacities, and circumstances are complex and ever-changing is not revelatory, particularly when describing those people who have cause to access services within mental health and homelessness sectors. What this study has revealed, however, is that the ways in which EBP and service-user participation have been theorised in ideal types and frameworks and defined in policy have failed to account for such complexity and variation. EBP as a process may more easily adapt and flex to such an environment than the misinterpreted notion of EBP as a set of proven practices, because it allows for a response to the specific circumstances and preferences of an individual. However, it still requires a degree of rational and informed decision making that, at certain times for certain people, is unrealistic and likely to be counterproductive. To simply transpose existing service-user involvement practices
onto a model of EBP would not work, because it is clear that there are already significant challenges for genuine, structural participation within the existing mechanisms. Again, the importance of open, trusting, and respectful relationships between practitioners and clients as a starting point emerges, as the importance of understanding changes in individual’s capacities and circumstances is highlighted. In respect to Figure 8.2, it is at this point that the importance of practitioner expertise and wisdom is revealed.

The issues of complexity also demonstrate that there are currently expectations on service users to adapt to fit within existing criteria of programs and services, rather than an impetus on service providers to adapt and flex to meet diverse and changing needs of service users. Participation has come, conveniently for service providers, to be conceived as formal mechanisms by which representatives take part in predetermined activities, to the detriment of structural notions of participation. The ways in which the access and engagement with services either inhibits or enables more full participation in society have been largely ignored and the complexities of participation have been oversimplified. Further, on an individual level the emphasis within neoliberal discourse of participation as consumer-oriented choice and decision making leaves little room to address issues of capacity, vulnerability, and crisis that impede the role in decision making for some people at some times. The outcomes for service use ought to be framed with parity of participation as an overarching principle, whereby service providers and policy makers assess and are held to account for the ways in which service users gain greater access to the full breadth of opportunities in society.
Implications

Evidence-based practice

The prevalent confusion regarding EBP and the meaning of evidence, among service providers and service users, pertains to two key points. First, the emphasis on EBP advocated in policy documents, such as *The Road Home* white paper (Australian Government, 2008), requires clearer directions for implementation, supported by resources and training in how to actually *do* EBP. Secondly, the failure for EBP to meet its promises of accountability and transparency has resulted from EBP’s failure to account for service-user expertise. Subsequently, interpretations of EBP have been inconsistent and service providers have improvised its implementation to attempt to make the idea workable within the real-life circumstances of human service delivery. EBP is worth doing, but it cannot simply be transferred from evidence-based medicine. Further work needs to be done to develop a realistic and achievable model for Australian human services which recognises the diversity of service providers (government and non-government) and which emphasises the frame of service-user expertise, preferences, values, and experiences. This requires a pragmatic approach to the concept of evidence and recognition of the intrinsically political nature of both research and service-user participation within the policy-making process.

Implication 1: Service providers need training and resources to facilitate the EBP process

This study reveals the importance of conceptualising EBP as a process, not as a set of proven practices. However, to enact this process requires service providers to have relevant professional capacities and resources. It is insufficient for policy to espouse the
importance of EBP without attaching the necessary professional development activities and resources to implement. While this study has focused on the perspectives and participation mechanisms of service users, the implementation of EBP by service providers is an essential component. This study has found that it is inadequate to rely on a participatory model of EBP which assumes service users have the interest, capacity, and resources necessary to source and appraise evidence themselves. To engage the most marginalised service users, such as those people accessing mental health and homelessness services, service providers must be able to facilitate the process of EBP. Intrinsic to this process is the professional capacity to engage with service users in a respectful manner, build relationships, and assess fluctuations in capacity. This is not a straightforward proposition because human services, particularly homelessness services, are delivered by a diverse range of government and non-government agencies and funded through a variety of means. Further, the workers within this multifarious setting represent a range of different professions and qualifications, including volunteers. As such, the introduction of EBP training within formal education institutions, through social work and social science degrees and community service certificates and diplomas, is important, but insufficient. Rather, policy initiatives, such as the additional funding for research into homelessness announced by the Australian Government (Department of Families Housing Community Services and Indigenous Affairs, 2009) need to include funding to support the implementation of processes relevant to EBP (such as retrieval and appraisal of evidence), as well as access to evidence sources, such as databases and journals, to support EBP. Such training and development initiatives must also acknowledge the engagement of service users and relationship-building processes as an intrinsic component.
Implication 2: Models for the inclusion of service users in research need to be developed and tested

Rigid and positivistic notions of evidence do not do justice to the complexities and subjective nature of human service users. If EBP is to achieve its claims of accountability, transparency, and collaboration, service-user expertise must be incorporated. Given that this study has demonstrated the importance of considering participation at individual and representative levels, the role of the service user in EBP must similarly be considered at these levels. At a representative level, service-user expertise has an important contribution to make to research and to generating the evidence base. The challenge is to maintain methodological rigour and reliability while introducing the intrinsically subjective and biased perspectives of service users. To do so requires effective collaboration and partnership between researchers and academics and service-user representatives, ensuring that service users who take part in research processes are provided training, access to technology and resources, and mentoring support. The perception of tokenistic participation practices frequently noted by service users in this study provides a caution for the ways in which service users might be engaged in research activities. It actually requires researcher bodies and institutions to change the way in which they do their business, to adapt resources, physical spaces, timelines, and meeting protocols such that they are accessible to service users. Further, service users need to know upfront the likely extent and impact of their contribution and to be provided feedback and follow up throughout the research process.

There needs to be a reduced emphasis on EBP as what works to avoid pressure on researchers, including service-user researchers, to demonstrate effectiveness of interventions and strategies in which they have strong personal belief. Pawson’s (2006) realist synthesis approach is enormously valuable within such a participatory research
model, because this approach is concerned with drawing out the aspects of interventions that are effective or ineffective within particular contexts. As such, researchers with personal attachment to certain interventions may actually demonstrate which aspects of the intervention are useful and make more insightful claims about the various elements of the intervention (i.e., research may show that an intervention does not achieve the outcomes it sets out to achieve, but it may also show that the intervention has a strategy for engaging with clients that is effective and replicable in other settings).

The above recommendations recognise that, as shown in this study, the failure for EBP to gain traction, and its tendency to be misinterpreted, derive from the failure to effectively account for the value of service-user expertise as an important frame and complement for empirical types of knowledge. However, what remains unclear is the extent to which the involvement of service users in research activities, in generating the evidence base, actually impacts outcomes. Further research is required to ascertain the actual impact and effect of service-user participation in research activities and to explore as yet unfounded claims regarding improved relevance and applicability of research as a result of service-user input. The literature reviews, supported by the small sample of findings derived from service users in this study who had taken part in research activities, indicate that participatory action type research methods have been common vehicles for service-user involvement in research, closely related to notions of emancipatory research. In such models, the emphasis is on the service-users’ involvement as a right and on the research process as an opportunity for empowerment and development for the service user. However, this study has demonstrated that a rights-based approach to participation is insufficient. Service users taking part in representative activities want to be part of problem-solving and systems-improvement efforts. As such, future research needs to consider the extent to which the participation
of service users in a variety of research methods and research roles actually impacts the quality, reliability, relevance, and applicability of research outcomes.

**Participation**

*Implication 3: Rights-based and consumerist notions of participation are insufficient for achieving social justice*

The literature reviews in this study provided an early indication of the dichotomous conceptions of participation as rights-based (citizenship) and as market-based (consumerism), theorising that to examine participation within a social justice framework required the type of multi-faceted notion afforded by Fraser’s (2001) parity of participation model. The findings affirm concerns about the inadequacy and inappropriateness of participation as a rights-based or consumerist approach, revealing important considerations for the future development of the concept of participation. Table 8.2 summarises the key strengths and challenges for notions of participation as rights-based and consumerism as derived from this study. It also outlines key challenges and opportunities afforded by the concept of parity of participation as it pertained to this study of service users and EBP.
### Table 8.2: Implications for participation frameworks

<table>
<thead>
<tr>
<th>Participation as right</th>
<th>Participation as consumerism</th>
<th>Participation as social justice/parity of participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Representative participation</td>
<td>Individual participation</td>
<td>Capacity for individual and representative notions of participation</td>
</tr>
<tr>
<td>Results in legislated and formal mechanisms for</td>
<td>Provides power and independence for those with necessary capacity</td>
<td>Encompasses aspects of rights-based and consumerist approaches</td>
</tr>
<tr>
<td>service-user input</td>
<td>and resources (such as internet access) for independent decision</td>
<td></td>
</tr>
<tr>
<td>Treats the act of participation as the end goal,</td>
<td>Requires capacity and resources (such as internet access)</td>
<td>Recognises that single issue of homelessness or mental illness does not reflect full extent of exclusion and marginalisation</td>
</tr>
<tr>
<td>such that having a seat at the table is seen as</td>
<td>for independent decision making that service users, particularly in crisis, do not have</td>
<td></td>
</tr>
<tr>
<td>sufficient acknowledgement of the right to participate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service-user involvement instead of meaningful participation</td>
<td>Exacerbates economic inequalities because those who can afford to pay for private services have greater choice</td>
<td>Emphasises responsibility of authorities to change, rather than of service users to adjust and adapt</td>
</tr>
<tr>
<td>Service users given the right to participate, but not necessarily the means (such as skills, technology, confidence, appropriate settings)</td>
<td>Implies availability of diverse options for treatment and services, when in fact there are few options or choices to be made in regard to services.</td>
<td>Underestimates centrality of identity to service user perceptions of disparity</td>
</tr>
<tr>
<td>Power retained with authorities as they control opportunities for participation</td>
<td>Implies active decision to consume services, when in fact people are often forced into service use through poverty or poor health</td>
<td>Supports examination of complexities and interconnections between aspects such as poverty and participation</td>
</tr>
<tr>
<td>Leads to tokenistic practices</td>
<td>Leads to further marginalisation of vulnerable people</td>
<td>Needs further development to translate to meaningful/operational actions</td>
</tr>
</tbody>
</table>

Examining participation in relation to evidence-based policy making and practice was useful within this study way to explore the appropriateness and usefulness of various interpretations of participation. EBP was seen to have strong associations with
neoliberal approaches to human service delivery and has gained prominence in tandem with the notion of social inclusion, which has a focus on employment as a realisation of participation. From this theoretical perspective, the study was able to draw out the way in which the treatment of service users as consumers had impacted on their decisions and outcomes regarding human service use. At their most vulnerable, service users did not have the means to actively consume, but for some, as their confidence grew and as their circumstances stabilised, they found that mechanisms such as private service provision expanded their opportunities and independence (particularly for mental health service users, homelessness service users continued to have little economic power to consume housing in the private market). Similarly, by exploring EBP within a social justice framework, issues regarding rights-based approaches to participation emerged, which often underpinned the relationship between government and non-government agencies and the service-user forums they supported (such as legal/advocacy services and homelessness consumer advisory groups). Agencies engaged with service users in recognition of their right to participate and service users (at least those with the confidence and resources to do so) took up the opportunity to exercise that right. However, the service users in this study revealed that the rights-based approach had not engaged them sufficiently in actual decision-making processes and the outcomes of their participation were often unclear. They wanted a more tangible role in the problem-solving process. Further, this approach tended to result in representative modes of participation, whereas consumerism resulted in individualised modes.

This study, therefore, indicates that neither rights-based nor consumerist approaches to participation have sufficiently captured the aspirations and needs of highly marginalised service users, although each has offered some useful starting points in terms of engaging with service users and challenging power relationships. Parity of
participation has proved useful as a tool for testing the cogency of claims of participation and for framing the discussion of social justice, but further research is required to determine the extent to which a parity of participation (or a broader social justice) framework might actually change the outcomes for service users. It remains to be tested as to whether parity of participation can be operationalised as a device to shape and measure policy and practice approaches, or whether it is simply a useful heuristic device. The promise of parity of participation revealed in this study is its usefulness in examining the complex and interconnected aspects of participation that have tended to be oversimplified in existing service-user involvement strategies. However, a rigorous testing of the domains of recognition, redistribution, and representation as tools for developing and assessing human service policy, and as tools for shaping the ways in which services engage with service users, is needed. A case study approach would again be useful for such research, to examine, and even pilot, the implementation and operationalisation of parity of participation principles in the real context of Australian human service policy and practice.

Implication 4: Authorities (policy makers and service providers) need to change and adapt their ways of working to meet the needs of marginalised people

Service users reiterated concerns revealed in the literature review regarding EBP’s propensity to be authoritarian and top-down because it was misinterpreted as proven practices rather than as a process. However, this misinterpretation is revealing when considered alongside the critiques of participation that emerged from this study. Service users have become accustomed to strategies which seem to promise ‘empowerment’ and ‘opportunity’ to participate but which, in fact, do little to change the ways in which
decisions are made, at either individual practice or broad policy levels. The study reinforced the findings of Barnes (2008) and Hodge (2005) that participation practices had failed to shift power dynamics or to understand the personal and emotional nature of service-user input. EBP, despite its promise of accountability and transparency, was also viewed with scepticism by many for its potential to simply reinforce authoritarian power structures. To achieve notions of accountability, transparency, and collaboration implicit in models of EBP espoused by its supporters, requires an approach to participation of service users that sees authoritarians and decision makers (in policy and practice settings) change the way they work, rather than the current emphasis on service users adapting to existing environments and fora.

In relation to representative notions of participation, service users and service providers in this study expressed concern about the (paradoxically) exclusionary potential of participation practices, because they required service users to: (i) be able to function within professional settings, such as meetings and workplaces, (ii) the ability to read and interpret sophisticated and often numerous materials, and (iii) access to technologies, such as the internet. There were some service users who had developed high-level competencies in this type of representative participation activity and who had considered their efforts effective and successful. However, more common in this study were people who had made various attempts to engage in these types of activities only to become exhausted and frustrated or people who did not attempt to take part at all because they saw that they did not have the interest, capacity, or resources to do so.

There are three recommendations emerging from this analysis of the challenges for representative types of participation. First, it is recognised that there are service users with highly developed, professional-standard skills, who can make a valuable contribution as representatives, facilitators, and mediators in settings such as
workplaces and committees. However, training and mentoring is required to support people in these roles to maximise their involvement and to develop skills in advocacy to represent the views of peers. In addition, training is required for employers or committee members, where this type of participatory activity takes place, to ensure that protocols and processes recognise and use the expertise of service-user representatives in a transparent way. Consideration must also be given to the economic cost of participation for service users who are not employed within the sector in which they function as representatives and adequate financial support provided to recognise the value of service-user input. This study has highlighted the perception of service-user input as a specific and important type of expertise and, for representative participation efforts to be successful, it is clear that a financial value needs to be attached to that expertise (as it is for professionals). Despite the challenges, representative type participation activities within existing workplaces and fora should not be dismissed, because service users and service providers in this study indicated significant benefit had emerged when this was done well. However, this type of activity alone is insufficient for enacting participatory modes of evidence-informed policy making and practice.

Secondly, government and non-government decision makers need to diversify the ways in which they seek service-user input and expertise and adopt strategies which are suitable for heterogeneous mix of service users. Examples of such diversification and innovation include where the City of Sydney (2010) in its Homelessness Street Count has recognised the need to physically visit the locations where people are sleeping rough in order to quantify and build data on homelessness and New South Wales CAG (Doyle, Coleman, Oakley, & Malins, 2009) has recognised the need to gain feedback from mental health service users on discharge from mental health services.
Such mechanisms are promising because they glean service-user expertise in a way that is adaptive to the circumstances and situations of the service users. There is a fine line here between over-consultation, where service users become tired of providing their feedback and telling their story and under-consultation, where policy and practice occurs without the input of service users. Representative modes of participation are just that, representative, and not intended to canvas all opinions and ideas. It is important, however, to provide realistic expectations for service users regarding the intended use of their expertise and feedback about its impact, to maintain transparency and accountability. A genuine approach to participatory modes of EBP would demand stakeholders, such as policy makers, researchers, and service providers, to be more innovative in their service-user involvement strategies, adapting and flexing to the requirements of the service users rather than service users being required to professionalise in order to fit rigid approaches. Again, further research is required given that there are various models of representative participation currently in operation. These could act as test sites to examine the impact of strategies and explore the ways in which service-user expertise may contribute most effectively to policy making and service delivery decisions.

Thirdly, approaches to participation need to consider it not only as a means (for recognising a right), but also as an end goal. As per Implication 3, further work needs to be done to explore participatory parity, or another similar multi-faceted social justice framework, as a measure for the effectiveness of human services policy and practice. In measuring the effectiveness of participation, the key question is not whether service users were given the opportunity to participate but whether there were positive effects on economic, identity/cultural, and political opportunities for service users as a result of the policy or intervention. While service-user involvement at representative levels may
prove to be important (although further testing is required) in enhancing the relevance and applicability of policy and practice, what is most important is that the outcomes of policy and practice enhance opportunities to participate more fully in society. More service-user involvement does not necessarily lead to more participation and it is the actual impact on opportunities and capacities to participate in society that is most important. Service-user advocacy and advisory groups similarly need to refocus their strategies to consider less emphasis on involvement and move towards advocating for actual structural change.

**Implication 5: Service-user capacities, preferences, and values need to be understood by practitioners and used to shape the direction of interventions**

This study unearthed the diverse and rich meanings which service users attached to the notion of participation, indicating that the way they engaged with society on an individual basis and the way in which they engaged with human services as individual service users were also intrinsic ideas. Representative modes of participation will only ever capture the ideas of a necessarily limited group. However, individual interactions with services are the points at which each person may experience and contribute to a participatory model of EBP.

As shown in Figure 8.2, the recommendation emerging from this analysis of service-user expertise and evidence at an individual level is that, in order to enact the process of EBP, the service-user’s preferences, values, and unique circumstances serve as the starting point, or the frame, in which EBP occurs. The skill of the professional helper in such a process is to build an understanding of the service-user’s circumstances and preferences, often in situations where the service user is in crisis and may have impaired capacity to express these preferences and concerns. As per Implication 1,
given that human services are delivered by a diverse range of agencies and workers, the
standardisation of such an approach and the necessary skill development is not
straightforward. However, in accordance with the recommendations for EBP training
described in Implication 1, strategies to develop professional skills in understanding and
appreciating unique client values and preferences is a vital first step in such professional
development activity. This may include training in strategies like Ulysses Planning
(management planning described in Chapter 6) to account for the significant
fluctuations in client capacity to engage in decision making.

For service users, the very fact that their capacity to articulate their preferences,
values, and goals changes dramatically means that, interestingly, a participatory
approach to EBP need not demand the active involvement of service users at all times in
the decision-making process. However, as indicated in this study, for many service
users, as their knowledge and confidence grew and as their circumstances stabilised, the
expectation to take responsibility for decision making also grew. Further, the impact of
peer expertise in this process of building knowledge and confidence was pronounced.
As such, there may be a legitimate role for service-user advocates, consumer workers,
and service-user representatives in facilitating the relationship building and
communication necessary to understand unique client values and preferences. While
such a role has previously been envisaged as a predominantly rights-based approach,
regarding the right to advocacy and representation, it ought to be reconfigured to be
incorporated into a participatory EBP approach.

As indicated in Figure 8.3, the experience of accessing human services was
perceived as complex for service users and demanded them to cycle through various
referral and assessment procedures for different agencies in order to find the service
they felt suited them best (or to find one that in desperation would suffice for their
immediate need). The opportunities for a participatory approach to EBP are limited in such a model because the service user is continually adapting to meet the requirements of the services, limiting the honesty and depth of their engagement with the service. The adoption of the no wrong doors policies promoted in key mental health and homelessness documents (Australian Government, 2008, 2009) is essential to overcoming numerous, superficial, confusing interactions with services. To achieve such an approach requires restructuring of human services, because the present funding models exacerbate competition for limited resources, rather than rewarding the attainment of successful outcomes deemed important to the clients. Service providers need to have the flexibility and resources to respond to the diverse needs of service users and be resourced to spend appropriate time with them to develop the relationships necessary to build trust and communication so central to transparent, accountable evidence-based practice.

**Epilogue**

The impetus for this study came from a suspicion that tools such as EBP were being promised as silver-bullet solutions to issues that were highly complex and related to deep, structural and systemic flaws in the provision of human services. However, the study also recognised that EBP’s promise of more accountable, transparent, and research-informed human services was worthy of further exploration. The fundamental incompatibilities between the concepts of EBP and participation were apparent from the literature reviews, but further confirmed and more deeply understood through the process of interviewing service users, reiterating the challenges for adopting positivistic, objective (at least in intention, if not in actuality) modes of knowledge in highly subjective and emotive domains. The study postulated that by enhancing and improving
the ways in which service users participated in processes and mechanisms of EBP, aspirations to more accountable, transparent, and collaborative human services might be realised. The final assertion of the study is that to do so demands the adoption of a pragmatic view of EBP in which service users contribute to the evidence base at a representative level and shape the context for assessing evidence at an individual level.

Ultimately, this study provides an important reminder that human service policy and provision is concerned with humans, who are diverse, complex, and ever-changing beings. Time and time again throughout this study service users, and notably service providers, lamented the frustrations of trying to have their voice (values, aspirations, preferences, and needs) recognised within a system of services that felt confusing and inflexible. Whether it is EBP, or some future version of research-informed practice, the clear message is that the challenges for service users are structural and systemic and not easily or quickly addressed and require service users’ input to be fully understood and appreciated.

Tools like EBP have sought to provide certainty in the delivery of services to people living amid great risk and uncertainty. However, until evidence-based strategies recognise and adapt to the humanistic (and therefore complicated and dynamic) nature of the work of human services, their impact will be limited. Service users in this study have revealed the importance of trusting relationships and the ways in which they establish their own, often informal, networks of peers to glean information they consider relevant and reliable. They have stressed the vulnerability experienced during periods of crisis and the ways in which their expectations and requirements of service providers change during such periods. The system of health and human services was perceived as daunting and confusing and people considered their achievement of successful outcomes had occurred despite, not because of, the formal network of
services. To improve this experience of the system and transform it into an opportunity for improved participation in society, practice and policy making need to draw on rigorous and relevant bodies of empirical research and the expertise of the people who have survived the system, but do so in ways that recognise the difference in these contributions to knowledge.
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Appendices
Appendix A: Script for semi-structured interviews
INTERVIEW SCRIPT: Service user

Thanks for taking the time to be part of this research, I know that as a member of this service-user group you are likely to have a lot of demands on your time, so I really appreciate your effort in being here today.

You’ve read the information statement, but I’ll just tell you a little more about the research and give you the chance to ask questions before we get started. You may have already heard the term ‘evidence’ being talked about in relation to the services and treatments you access. This research is about what users of human services think about evidence and about how you use evidence. I won’t go into too much detail about what I think evidence means, because I don’t want to pre-empt any of your responses. I’ll be doing a series of interviews with service users, others from your service user group and service users from other groups. I’ll also be interviewing some of the professional workers from agencies associated with service users. After that I will look over the information and feedback from those interviews and use this to develop guidelines about how service users can participate in evidence-based practice and how service users can use evidence to meet their goals.

The interview is informal, so feel free to stop if you feel the need or to ask questions along the way. I’ll be recording the interview so I get an accurate record. It will then be transcribed, or written up, at which stage identifying information such as your name will be coded. The report and documents from this research will not identify you.

Have you got any questions before we begin?

1. What do you understand by the term ‘evidence’ and ‘Evidence-based Practice’?

INDIVIDUAL COMPONENT

2. A) Where do you get information about the issues or conditions that affect you and about treatments and services?

B) Do you do your own research and if so how do you go about it?

3. When you make a decision about treatment, what are the things that influence your decision? What kind of information do you use?

4. A) What services do you access or use?

B) To what extent do you think those services are ‘evidence-based’ and is this important to you?

C) Are workers at the services you access able to give you information about the evidence base informing treatments?

5. What type of information is most compelling for you? Eg. testimonials, word of mouth from other service users, scientific studies, journal articles, books, advertising
materials, advice of professionals, advice of others (eg. family, friends, religious leaders)

6. In what format do you prefer to receive information? Eg. face to face, brochures, online, TV

REPRESENTATIVE COMPONENT

7. What are the activities you are involved with as part of this service user group?

8. What do you hope to achieve by being a part of the group?

9. What are the differences between how professionals approach an issue and how service users do it?

10. Have you ever been involved in research, other than as a ‘subject’ (ie. Subject of an interview or participant in a trial)? Eg. conducted research, gave advice to researchers

11. Would you be interested in participating in research? What type of role do you think would be best and why? Eg. leading research, giving input to the research agenda, sitting on committees
Thank you for taking the time to be part of this research, I really appreciate your effort in being here today.

You’ve read the information statement, but I’ll just tell you a little more about the research and give you the chance to ask questions before we get started. You may have already heard the term ‘evidence’ being talked about in relation to the services and treatments you provide. This research is about what users of human services think about evidence and about how they use evidence. You are not expected to answer on behalf of service users, because they will be asked directly about their ideas and experiences. Your input is to get an idea about your professional experiences of service users’ needs and activities in relation to evidence. I won’t go into too much detail about what I think evidence means, because I don’t want to pre-empt any of your responses. I’ll be doing a series of interviews with representatives of service user groups and the professionals from agencies who work with those individuals and groups. After that I will look over the information and feedback from those interviews and use this to develop guidelines about how service users can participate in evidence-based practice and how service users can use evidence to meet their goals.

The interview is informal, so feel free to stop if you feel the need or to ask questions along the way. I’ll be recording the interview so I get an accurate record. It will then be transcribed, or written up, at which stage identifying information such as your name will be coded. The report and documents from this research will not identify you.

Have you got any questions before we begin?

1. What do you understand by the terms ‘evidence’ and ‘Evidence-based Practice’?

INDIVIDUAL COMPONENT

2. A) Do clients come to you with existing knowledge about their condition/issues and treatment options?
   
   B) Where do clients of your service get such knowledge about the issues or conditions that affect them and about treatments and services?
   
   C) What is your opinion of the quality of the information that clients are accessing outside your service?

3. A) How much evidence, and in what form, do you provide to clients about treatment options?
   
   B) Do you think you provide sufficient (in terms of quality and quantity) evidence to clients and what would sufficient evidence look like?
4. Do you think evidence is an influential factor when clients are making a decision about treatment options? What are other influential factors?

5. What is most compelling to you as a professional when identifying the recommended treatment for a client? Eg. scientific research, client preference, availability of resources, recommendation of other professionals

REPRESENTATIVE COMPONENT

6. What role/s do service users play in the governance and operation of your organisation?

7. Do service users have a role in determining the range of treatments to be offered and if so how does this work?

8. How does your organisation use and manage evidence? Is there a role for service users in this process?

9. Do you find that research evidence is relevant and applicable to the situations in which you work? If not, what role could service users have in addressing this?
Appendix B: Coding summary
**Hierarchical Name**

<table>
<thead>
<tr>
<th>Node Path</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>Nodes\Tree Nodes\ARC EBP Q20\accountability</td>
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</tr>
<tr>
<td>Nodes\Tree Nodes\ARC EBP Q20\client as partner in decisionmaking</td>
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<tr>
<td>Nodes\Tree Nodes\ARC EBP Q20\client feedback and expertise as evidence</td>
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<tr>
<td>Nodes\Tree Nodes\ARC EBP Q20\Cochrane, Campbell or systematic review</td>
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<tr>
<td>Nodes\Tree Nodes\ARC EBP Q20\EBP + client values</td>
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<td>Nodes\Tree Nodes\ARC EBP Q20\EBP + professional wisdom</td>
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<td>Nodes\Tree Nodes\ARC EBP Q20\importance of therapeutic relationship</td>
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<td>Nodes\Tree Nodes\ARC EBP Q20\information vs evidence</td>
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<tr>
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<tr>
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Appendix C: Research summary disseminated to participants
RESEARCH SUMMARY

Service-user perspectives on evidence: a tool for shaping human services?

Overview

The research explored service-user needs regarding policy making and service delivery and the ways in which service users might play a part in improving the use of evidence in human services in Australia. The study considered:

- the ways in which models of policy making and service provision within the homelessness and mental health sectors in New South Wales either inhibited or enabled the participation of people who had experienced homelessness or mental illness; and
- the potential for evidence-based approaches to policy making and service provision to enhance parity of participation.

A case study approach compared and contrasted the experiences and expectations of people who had used mental health services with those who had used homelessness services. The main data came from 11 interviews with mental health service users and 11 interviews with homelessness service users, with a sample of 11 service providers also interviewed to test for consistencies and tensions in perspectives. Key federal, state and regional policy documents relating to mental health and homelessness were examined to compare policy intentions with the actual experiences of service users. Preliminary findings were presented back to small focus groups with a total of 7 service users to test the accuracy and workability of findings.

This study was the first of its kind to examine the compatibility (or otherwise) of EBP and social justice. Respondents in both case studies revealed that EBP was poorly understood and had failed to make an impression on the experiences of the most marginalised service users. While ‘consumer’ participation was prevalent within mental health policy and practice, it was just emerging in the homelessness sector, and in both case studies respondents revealed concerns about participation, given their broad and multifaceted identities, fluctuating capacities and complex lives. The study found that overly simplistic and inflexible models of EBP and participation were unsuitable for these service users and that a process which emphasised the importance of relationship building between service users and service providers and which used the expertise and circumstances of individual service users as a lens through which to assess evidence would contribute to a model of EBP that fit within the social justice frame.
Comparison of key findings from case studies

<table>
<thead>
<tr>
<th>Homelessness</th>
<th>Mental health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emerging service user participation movement, citizen-based rights approach, yet to demonstrate impact.</td>
<td>Strong ‘consumer’ participation movement that has led to professional consumer roles and inclusion of recovery and participation in policy frameworks.</td>
</tr>
<tr>
<td>Challenge for participation mechanisms to engage the most vulnerable and move beyond tokenistic gestures.</td>
<td>Paradox of advocating for change from within the system and challenge for participation mechanisms to recognise individualistic and non-mainstream approaches. Potential for participation mechanisms to reinforce stereotypes and stigma and demand high skill levels and adaptability (excluding many service users).</td>
</tr>
<tr>
<td>EBP seen to be about research-supported practices, particularly housing first, rather than processes.</td>
<td>EBP seen to be about practices, not processes. As such concerns that EBP contradicts recovery by being top-down and medicalised.</td>
</tr>
<tr>
<td>Understanding of EBP</td>
<td>Understanding of EBP</td>
</tr>
<tr>
<td>Service users: 3 high, 4 medium, 4 none</td>
<td>Service users: 2 high, 6 medium, 3 none</td>
</tr>
<tr>
<td>Service providers: 1 high, 4 medium</td>
<td>Service providers: 3 high, 2 medium, 1 none</td>
</tr>
<tr>
<td>Strong federal policy framework emphasis on EBP, participation, and social inclusion, but fails to translate into implementation strategies at state and regional service provision levels</td>
<td>Consumer and recovery focused policy frameworks at all levels, with varying degrees of emphasis on EBP (and poorly conceptualised notions of evidence)</td>
</tr>
<tr>
<td>Lack of accountability to service users (only recourse to speak with their feet) and decision making seen as arbitrary</td>
<td>Importance of trusting that professionals can make good decisions when service users just need to concentrate on getting well (including trusting that professionals have done their research)</td>
</tr>
<tr>
<td>Service users exercising little power in decision making, at whim of providers, little real choice available.</td>
<td>Participation in decision making varies significantly between times of crisis/severe illness and periods of recovery, with mechanisms such as advanced planning a means to retaining power over decision-making processes.</td>
</tr>
<tr>
<td>Service user expertise highly valued by study respondents (but not seen to be valued in actual practice settings) as a tool to improving services, exercising the right to participate and in building the evidence base.</td>
<td>Service user expertise seen as unique and central to recovery. Attempts to legitimise service user expertise through formal education and professionalisation of consumer roles.</td>
</tr>
<tr>
<td>Word of mouth and recommendations of fellow service users were most important source of information (far more important to decision making than empirical evidence).</td>
<td>Doing own research (books, library, internet, conferences, peer support forums) generally important during recovery, after moving past crisis stage. Ambivalence about importance of evidence in decision making.</td>
</tr>
<tr>
<td>Experience of service use a long way from ideal types of EBP and participatory decision making - not about making choices, but rather taking what is on offer.</td>
<td>Experiences of partnered decision making were highly valued but there were limited options from which to choose.</td>
</tr>
<tr>
<td>EBP seen as a potential tool for improving accountability.</td>
<td>EBP seen as professional responsibility, although cynicism about the bias of evidence towards medication-oriented treatment.</td>
</tr>
<tr>
<td>Service users saw a role for themselves in research activities and generating the evidence base.</td>
<td>Varied interest in research activities, from experience in leading, designing and advising research to no interest.</td>
</tr>
</tbody>
</table>

"Well you know, there is not one solution, we're all different people, different problems at different stages of life." (Penny*, homelessness service user)  

"I know the things that can change just from my life and my experience and I know what's happening and it's just ... I have empathy with the people who use the system and who don't know what I know. And I know that what I have learnt is useful and I want to share that.” (Tara, mental health service user)
Conclusions and implications

Service-user capacities, preferences, and values need to be understood by practitioners and used to shape the direction of interventions

The experience of accessing human services was complex for service users and demanded them to cycle through various referral and assessment procedures for different agencies in order to find the service they believed best suited them (or to find one that, in desperation, would meet their immediate need). ‘No wrong door’ policies, reduced competition for funding and resources and a flexible, personal approach to the idea of a ‘successful outcome’ are important to a participatory EBP process.

Service providers need training and resources to facilitate the EBP process

Service providers must be able to facilitate the process of EBP. Essential to this process is the professional skill to engage with service users in a respectful manner, build relationships, and assess fluctuations in capacity, understanding that the ways in which service users make decisions.

Models for the inclusion of service users in research need to be developed and tested

Service-user expertise has an important contribution to make to research and to generating the evidence base. This requires collaboration and partnership between researchers and academics and service-user representatives, ensuring that service users who take part in research processes are provided training, access to technology and resources, mentoring support and feedback. Service users taking part in representative activities want to be part of problem-solving and systems-improvement efforts.
As such, future research needs to consider the extent to which the participation of service users in research impacts the quality, reliability, relevance, and applicability of research outcomes.

**Participation needs to be about social justice**

Treating participation as a right has led to representative types of participation and formal mechanisms for service users to take part, but many of these were seen as tokenistic and excluded service users who didn’t have particular resources and skills necessary to take part. Treating participation as consumerism was also a problem, because there was not actually a diverse range of services to ‘choose’ from and because many of the service users lacked the resources, such as finances, to purchase the services they considered better quality. Instead it is useful to think about participation in terms of people’s opportunities to take part in the full spectrum of society.

**Authorities (policy makers and service providers) need to change and adapt their ways of working to meet the needs of marginalised people**

To achieve accountability, transparency, and collaboration in EBP requires an approach to participation of service users that sees decision makers (in policy and practice settings) change the way that they work, rather than the current emphasis on service users adapting to existing environments and forums. This requires training and mentoring for service users in representative roles, as well as for their employers and fellow committee members, provision of financial support for service users in representative roles and a more diverse range of participation mechanisms.

If you would like further information about this study please contact Kate Davies, Research Institute for Social Inclusion and Wellbeing, University of Newcastle at kate.davies@uon.edu.au.

*names of research participants have been changed to maintain anonymity.*
Appendix D: Participant information statements
Information Statement for the Research Project:
Service-user perspectives on evidence: a tool for shaping human services?

Document Version 2; dated 7/9/2009

You are invited to participate in the research project identified above, which is being conducted by Kate Davies from The Australian Institute for Social Inclusion and Wellbeing at the University of Newcastle.

The research is part of Kate Davies’ studies at the University of Newcastle, supervised by Professor Stephen Webb and Professor Mel Gray from The Australian Institute for Social Inclusion and Wellbeing. The research will also contribute to a major study being undertaken by The Australian Institute for Social Inclusion and Wellbeing on barriers to the implementation of Evidence-based Practice in human services, which will examine professional and organisational challenges to using evidence.

Why is the research being done?

The purpose of the research is to find out how the people who use human services (the ‘consumers’) feel about the type of information and evidence that is available to them about these services. The types of human services that will be investigated might include housing programs, mental health services, drug and alcohol programs, employment programs and disability support programs. The research will look at the ways that consumers can have input to evidence-based practices and how they can use evidence to get the outcomes they value.

The large project being undertaken by The University of Newcastle about the barriers to implementing evidence-based practice in the human services in Australia will undertake a national survey, interviews and case studies of human service professionals and organisations. It is aims to contribute to more effective and accountable provision of human services.
**Who can participate in the research?**
We are inviting people who have an active role in consumer groups related to human services to participate in the research. We will do three case studies of consumer groups and the agencies that they work with.

**What choice do you have?**
Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you.

If you do decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

**What would you be asked to do?**
If you agree, you will be asked to participate in an interview with the researcher and/or a focus group with the researcher and other representatives from your consumer group.

During the interview you will be asked questions about:

- The information and resources you use to help make decisions about treatments and services;
- How much, and what type of evidence you expect to be provided by workers and organisations regarding the services and treatments they offer;
- How you find out information about the conditions or issues that affect you.

You will also be asked about your role in the consumer group and whether you have been involved in helping to generate evidence or involved in research activities. You will get the chance to give your ideas about how consumers can take part in research activities and the kind of model that would help consumers get access to the evidence they feel they need to make decisions about their care.

If you choose to participate in the interview you will be invited back at a later date, to be part of a focus group to test and discuss the findings from the research. You can choose only to participate in the interview. If you choose not to participate in the interview, you will still have an opportunity to participate in the focus group. The focus group will bring together up to six members at a time from your consumer group to talk about what has been learnt from the research project. Models and ideas about how evidence can help consumers make better decisions will be presented. Strategies for consumers to become involved in evidence-based practices will also be discussed.

**How much time will it take?**
The interview will be a face to face conversation with the researcher and so the length of the discussion will vary. It is expected that the interview will last about one hour.

The focus group will take the form of a group discussion, facilitated by the researcher. It is expected it will take about two hours.

There will be opportunities for a break and you will be able to stop at any time you feel the need to.

**What are the risks and benefits of participating?**
The main benefit to taking part is to contribute your ideas and experiences to research about the services that affect you.

There are no risks identified with participating in this project.

**How will your privacy be protected?**
Any information collected by the researchers which might identify you will be stored securely and only accessed by the researchers unless you consent otherwise, except as required by law. Interviews and focus groups will be recorded and transcribed. Should you wish to do so, you will have the opportunity to review the transcription and edit or erase your contribution. The interview material and focus group transcripts are anonymous. They will identify organisation and consumer group names, but not the individuals within those groups.

Participants in the focus group discussions will be asked to sign a confidentiality agreement, asking that they respect the privacy of other participants and that they do not speak about the content of the focus group to outside parties.

Data will be retained for at least 5 years at The Australian Institute for Social Inclusion and Wellbeing at the University of Newcastle.

**How will the information collected be used?**
The information collected will contribute to a thesis for Kate Davies’ degree. It is also hoped that the findings from the research will be presented at international conferences and submitted for publication to journals in social work.

Individual participants will not be identified in any reports or publications arising from the project.

Participants will be offered at least a summary of the research results written for their information. Please note that the summary of results will only be provided to those participants who have given their informed consent to take part in the project and who have indicated that they wish to receive a copy of the results. A copy will also be provided to the relevant consumer groups.

**What do you need to do to participate?**
Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher.

If you choose to participate the researcher, Kate, will contact you to arrange a suitable time and venue for the interview or focus group. You will receive a gift voucher to the value of $25 upon completion of each interview and/or focus group you participate in, to recognise the value of your time and effort and costs associated with taking part.

If you would like to participate, please complete the attached Consent Form and return it in the reply paid envelope provided. I will then contact you to arrange a time that suits you for the interview.

**Further information**
If you would like further information please contact Kate Davies or Professor Stephen Webb on the details above.
Thank you for considering this invitation.

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Professor Stephen Webb  
Supervisor

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Professor Mel Gray  
Supervisor

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Kate Davies  
Researcher

Complaints about this research
This project has been approved by the University’s Human Research Ethics Committee, Approval No. H- H-2009-0233.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au.
Information Statement for Service Providers regarding the Research Project
Consumer perspectives on evidence: a tool for shaping human services?

Document Version 2; dated 7/9/2009

You are invited to participate in the research project identified above, which is being conducted by Kate Davies from The Australian Institute for Social Inclusion and Wellbeing at the University of Newcastle.

The research is part of Kate Davies’ studies at the University of Newcastle, supervised by Professor Stephen Webb, Professor Mel Gray from The Australian Institute for Social Inclusion and Wellbeing. The research will also contribute to a major study being undertaken by The Australian Institute for Social Inclusion and Wellbeing on barriers to the implementation of Evidence-based Practice in human services, which will examine professional and organisational challenges to using evidence.

Why is the research being done?

The purpose of the research is to find out how the people who use human services (the ‘consumers’) feel about the type of information and evidence that is available to them about these services. The types of human services that will be investigated might include housing programs, mental health services, drug and alcohol programs, employment programs and disability support programs. The research will look at the ways that consumers can have input to evidence-based practices and how they can use evidence to get the outcomes they value.

The large project being undertaken by The University of Newcastle about the barriers to implementing evidence-based practice in the human services in Australia will undertake a national survey, interviews and case studies of human service professionals and organisations. It is aims to contribute to more effective and accountable provision of human services.

Who can participate in the research?
We are inviting people who have an active role in consumer groups related to human services to participate in the research as the ‘consumers’. We are also inviting representatives from agencies or organisations which provide services or make policy related to these consumer groups. We will do up to three case studies of consumer groups and the agencies that they work with.

What choice do you have?
Participation in this research is entirely voluntary. Only those organisations and people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you.

If you decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies your organisation.

What would you be asked to do?
If you agree, you will be asked to participate in an interview with the researcher. During the interview participants will be asked questions about:

- Their understanding and use of Evidence-based Practice;
- The expectations that clients have of them to provide and use evidence in their practice or policy making;
- The ways that service users participate in their practice or policy making.

They will have the opportunity to provide their ideas about how consumers can take part in research activities and the kind of model that would help consumers get access to the evidence they feel they need to make decisions about their care.

Those who participate in the interview may be invited back at a later date to be part of a focus group to test and discuss the findings from the research. Participants can choose only to participate in the interview. The focus group will bring together up to six service providers and/or policy makers to talk about what has been learnt from the research project. Models and ideas about how evidence can help consumers make better decisions will be presented. Strategies for consumers to become involved in evidence-based practices will also be discussed.

How much time will it take?
The interview will be a face to face or telephone conversation with the researcher and so the length of the discussion will vary. It is expected that the interview will last about one hour.

The focus group will take the form of a group discussion, facilitated by the researcher. It is expected it will take about two hours.

There will be opportunities for a break and participants will be able to stop at any time they feel the need to.

What are the risks and benefits of participating?
The main benefit to taking part is to contribute ideas and experiences to research about the services that affect members and consumers of your organisation.

There are no risks identified with participating in this project.

How will your privacy be protected?
Any information collected by the researchers which might identify participants will be stored securely and only accessed by the researchers unless consent to do otherwise is provided, except as required by law. Interviews and focus groups will be recorded and transcribed. Should participants wish to do so, they will have the opportunity to review the transcription and edit or erase their contribution. The interview material and focus group transcripts are anonymous.

Organisations and consumer group names may be identified in case studies, but the names of individuals within those groups will not be identified.

Participants in the focus group discussions will be asked to sign a confidentiality agreement, asking that they respect the privacy of other participants and that they do not speak about the content of the focus group to outside parties.

Data will be retained for at least 5 years at The Australian Institute for Social Inclusion and Wellbeing at the University of Newcastle.

How will the information collected be used?
The information collected will contribute to a thesis for Kate Davies’ degree. It is also hoped that the findings from the research will be presented at international conferences and submitted for publication to journals in social work.

Individual participants will not be identified in any reports or publications arising from the project. Organisation and consumer group names will be identified for the purposes of providing case studies.

Participants will be offered at least a summary of the research results written for their information. Please note that the summary of results will only be provided to those participants who have given their informed consent to take part in the project and who have indicated that they wish to receive a copy of the results. A copy will also be provided to the relevant consumer groups and organisations.

What do you need to do to participate?
Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher.

If you choose to participate the researcher, Kate, will contact you to arrange a suitable time and venue for the interview or focus group.

If you would like to participate, please complete the attached Consent Form and return it in the reply paid envelope provided. Kate will then contact you to arrange a time that suits you for the interview.

Further information
If you would like further information please contact Kate Davies or Professor Stephen Webb on the details above.

Thank you for considering this invitation.

-------------------------------------------------------------------------
Professor Stephen Webb
Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H- H-2009-0233.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au.
Appendix E: Participant consent form
Consent Form for the Research Project:

Consumer perspectives on evidence: a tool for shaping human services?


I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to the following (circle YES to those activities you agree to participate in, and circle NO to those activities which you do not agree to participate in):

- Participating in an interview and having it recorded
- Participating in a focus group and having it recorded

I would like to receive a copy of the study results

I understand that my personal information will remain confidential to the researchers.

I have had the opportunity to have questions answered to my satisfaction.

Print Name: ____________________________

Contact Details (for arranging an interview or focus group):
Telephone: ___________ Email: ____________________________

Signature: __________________________ Date: ____________