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Practising Social Inclusion

This book explores what is known about what works and why in promoting or practising social inclusion in the variety of fields that deal with human health and wellbeing. It is concerned with research into and/or reflection on the practice of a wide variety of health and social welfare (human services, social care) professionals, as well as community workers, activists, policy makers and researchers.

Our earlier book, *Theorising Social Exclusion*, focused particularly on the role of social and cultural factors in the creation and recreation of categories of exclusion and inclusion. It addressed how individuals and groups come to be seen, or experience themselves, as included and/or excluded. This subsequent book, *Practising Social Inclusion*, will move beyond identifying mechanisms and processes of exclusion to providing answers to the important question of how to actually work towards inclusion, drawing on the research and/or reflective practice that the authors have engaged in. The book is global in its scope, with chapters relating to socially inclusive health and social welfare practice internationally.

The book contributes to the growing debates on social inclusion, which hitherto have often been confined in terms of discipline (e.g. public health, social work), field of practice (e.g. education, disability or youth) or geography (from a single country or continent). Furthermore, the book explores the full range of practice dimensions, including policy, service design, service delivery, community life and research.

This research-based book is relevant to a wide range of different readerships globally. The book addresses issues of concern for those engaged in debates about the provision of health, social welfare and other public services. It will be of interest to academics, policy makers and practitioners in a wide range of fields, including health sciences, public health, health promotion, occupational therapy, disability studies, social work, social policy, social sciences and education.

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Practising Social Inclusion

Edited by
Ann Taket, Beth R. Crisp,
Melissa Graham, Lisa Hanna,
Sophie Goldingay, Linda Wilson
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# Acronyms

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<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABI</td>
<td>Acquired brain injury</td>
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<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<td>ADB</td>
<td>Asian Development Bank</td>
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<tr>
<td>AEDI</td>
<td>Australian Early Developmental Index</td>
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<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>AIPC</td>
<td>Australian Institute of Primary Care</td>
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<tr>
<td>ASD</td>
<td>Autistic spectrum disorder</td>
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<tr>
<td>AT</td>
<td>Assistive technology</td>
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<tr>
<td>ATSI</td>
<td>Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>BMI</td>
<td>Body mass index</td>
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<tr>
<td>CBPR</td>
<td>Community-based participatory research</td>
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<tr>
<td>CBT</td>
<td>Cognitive-behavioral therapy</td>
</tr>
<tr>
<td>CDC</td>
<td>US Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>COAG</td>
<td>Council of Australian Governments</td>
</tr>
<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>CSCI</td>
<td>Commission for Social Care Inspection (UK)</td>
</tr>
<tr>
<td>CSO</td>
<td>Community services organisation</td>
</tr>
<tr>
<td>CyBER/M4M</td>
<td>Cyber-Based Education and Referral/Men for Men</td>
</tr>
<tr>
<td>DHS</td>
<td>Department of Human Services (Victoria, Australia)</td>
</tr>
<tr>
<td>DOHA</td>
<td>Department of Health and Ageing (Australia), in 1988 was</td>
</tr>
<tr>
<td></td>
<td>Department of Health and Aged Care</td>
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<tr>
<td>EU</td>
<td>European Union</td>
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<tr>
<td>FASD</td>
<td>Foetal alcohol spectrum disorder</td>
</tr>
<tr>
<td>FBO</td>
<td>Faith-based organisations</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner, family doctor</td>
</tr>
<tr>
<td>GMB</td>
<td>GROUP Ministries Baltimore</td>
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<tr>
<td>GPC</td>
<td>General Pharmaceutical Council (UK)</td>
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<tr>
<td>HIV/AIDS</td>
<td>Human immunodeficiency virus/acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>HOPE</td>
<td>HIV Outreach, Prevention, and Education curriculum</td>
</tr>
<tr>
<td>IASSW</td>
<td>International Association of Schools of Social Work</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
</tr>
<tr>
<td>ICT</td>
<td>Information and communication technology</td>
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</table>
1 Scoping social inclusion practice

Ann Taket, Beth R. Crisp, Melissa Graham, Lisa Hanna and Sophie Goldingay

Introduction
The overall aim of this book is to explore what is known about promoting or practising social inclusion in the variety of fields that deal with human health and wellbeing. Our emphasis is on the examination of what works and why. So, the book is concerned with research into and/or reflection on a wide variety of professional and community practice.

Our earlier book, Theorising Social Exclusion (TSE, Taket et al. 2009a) focused particularly upon the role of social and cultural factors in the creation and recreation of categories of exclusion and inclusion, and this is retained here as a strong focus. TSE examined how individuals and groups come to be seen as, or experience themselves as, included and/or excluded. The book illustrated how exploring the processes that lie behind exclusion and connectedness helps us understand how these arise, and are played out in everyday life. While the examples presented in TSE provided theoretical insights into how practitioners and policy makers may shape their practice to improve wellbeing and reduce social inequity, this book, Practising Social Inclusion, provides concrete examples of socially inclusive policies and practices and reflections on their outcomes.

TSE noted that many different understandings about social exclusion are present in the academic literature and within policy discourses. A range of definitions of social exclusion exist, produced in diverse circumstances, each definition to some extent meeting different needs. TSE's purpose was not to craft a detailed genealogy of the term, but rather to illustrate its variety and the necessity of paying close attention to the particular definition(s) that come into play in different policy and practice situations. For the purposes of the present book, our understanding of social exclusion is best expressed in the following, which is created from a merging of two different sources:

Social exclusion is a complex and multi-dimensional process driven by unequal power relationships interacting across four main dimensions – economic, political, social and cultural – and at different levels including individual, household, group, community, country and global levels. It involves the lack or denial of resources, rights, goods and services, and the
The intersectional framework we set out in TSE had a number of distinctive features in its approach to social exclusion. By extension, these features also underpin the approach to socially inclusive practice we present in this book. First, social inclusion is dynamic, multiple and contingent. Individuals, groups, and communities will usually experience differing degrees of inclusion and connectedness in different domains of life, and these change through time as both external and internal factors change. This complexity demands a nuanced and sophisticated approach to tackling exclusion in both policy and practice. All too often, however, responses are situated within the silo of a particular sector and are based on a binary distinction between excluded and included. In responding to this complexity, we emphasised the importance of a focus on the privileged, as a distinct group within the broader category of the included, and on intersectoral or multisectoral approaches to addressing exclusion. Second is the importance of language in the creation and recreation of exclusion, inclusion and connectedness. We make sense of the world, our understandings of it, and our place in it, through language; our use of language creates, contests and recreates power, authority, and legitimation (Rorty 1989). The discursive construction of social experience sets limits and constraints on the positions of exclusion, inclusion and connectedness that individuals and groups can take up. However individuals and groups are active, resistant agents in these processes and can shape the realm of discursive possibilities. In terms of successful inclusive practice, language is therefore also important.

Connected to this is the importance of a shift in view about identity, as constituted rather than determined (Gordon 1980, Butler 1990). Our analysis of inclusion/exclusion is based on a position of theoretical pluralism, discussed elsewhere as pragmatic pluralism (Rorty 1989; Taket and White 2000) or adaptive pluralism (Chambers 2010). Such a theoretical stance is necessary to do justice to the complexity of the forces and relationships that shape individuals’ and groups’ experiences of exclusion/inclusion and being excluded/included.

TSE proposed that social exclusion and connection can be considered in three broad spheres of action: individual agency, community and society. This approach has similarities to that of Gallie (2004), who presents his ideas on social isolation by describing three major spheres of sociality: the primary (micro) sphere involving connection to immediate family and household residents; the secondary (meso) sphere regarding interactions with people outside of the household; and the tertiary (macro) sphere involving participation in external structures and the broader environment. There are also resonances with three levels (biographical, life-world and structural) used in Steinert and Pilgram (2007), as well as with the relational framework described in Abrams
and Christian (2007), whose analysis distinguishes four different elements: the actors in an exclusion relationship (sources and targets of exclusion); the relationship context (across a series of levels from intrapersonal through to societal and trans-national); the modes/forms of exclusion (ideological/moral, representational, categorical, physical, communicative); and the dynamics of the exclusion relationship (the why and when exclusion happens).

TSE’s analysis of how exclusion arises and is perpetuated points to the need for change in both policy and practice. There is a need to move away from ‘victim-blaming’ approaches that construct exclusion as a deficiency or shortfall in the excluded, rather than arising as a consequence of the complex interactions between a wide range of factors, including the actions of the privileged. The growth of critical and anti-oppressive approaches to practice in social work, as well as the growth of empowerment and strengths-based approaches in health promotion, public health and other public sector services is a partial response to this, but needs to become more widespread in implementation. This will not be an easy task to achieve, as it demands, in many instances, a change in service ethos at all levels of practice.

Social inclusion, according to the theoretical framework utilised in this book, occurs when the participation or involvement achieved in any particular case can be demonstrated to be real rather than tokenistic or manipulative; in other words, reaches the top three rungs of Arnstein’s ladder of citizen participation (Arnstein 1969) as shown in Figure 1.1, i.e. citizen control, delegated power and partnership. Achievement of such levels of participation has far-reaching consequences for those involved: ‘Autonomy – how much control you have over your life – and the opportunities you have for full social engagement and participation are crucial for health, well-being and longevity’ (Marmot 2004: 2).

The individual’s experience of inclusion as being associated with feelings of connectedness and belonging as well as right or entitlement then is of vital importance. Social inclusion can also thus be seen as the fulfilment of civil,

**Figure 1.1** Arnstein’s ladder of citizen participation

Source: adapted from Arnstein (1969)
political, economic, social and cultural rights (Room 1999; Renner et al. 2007). Rights to participation in political, social and cultural life in society are set out in the Universal Declaration of Human Rights and in the various human rights instruments within the United Nations (UN) system. Rights-based approaches have been developed and used successfully to implement rights to participation (Taket 2012) as has community-based participatory research (considered further in the later section on research).

Klasen (n.d.) suggests a rights-based approach to challenging social exclusion has four advantages, similar to the advantages of Sen’s capabilities-based approach (Sen 2000): emphasising firstly that the inability to participate in, and be respected by, mainstream society is a violation of a basic right that should be open to all residents; we note the difference implied if the term ‘citizens’ were to be substituted for ‘residents’. Rights-language considerably strengthens the case for society to ensure that it enables participation and integration of all its members, while also highlighting the role of political, economic and social factors in creating (and maintaining) exclusion in contrast to phrasings that position social exclusion as a ‘social’ or ‘welfare’ issue. Secondly, a rights-based approach calls for equal freedoms for all, and thus makes an important distinction between individual choice not to participate in mainstream society, and inability to do so. Thirdly, the diverse abilities of people to make use of opportunities are recognised. Achieving equal capabilities (or the ability to exercise civil and social citizenship rights) may require extra efforts by society to provide equal capabilities to all people. Fourthly, a rights-based approach focuses on ends and not on means. In the remainder of this chapter, and throughout the different parts of the book, different examples of such rights-based approaches to social inclusion are highlighted.

When considering the practice of social inclusion, some aspects of Foucault’s theorisation of power are relevant. A critical scrutiny of the construction of the subject/identity and the operation of power is important, as the point of its operation is also the point at which resistance is/can be sited (or sighted). Three of Foucault’s methodological precautions in looking at power are of particular pertinence: to examine domination and the material operators of power; to study ‘power at the point where its intention . . . is completely invested in its real and effective practices’ (Foucault 1976: 97); to analyse power as something that circulates.

The past thirty years have seen a variety of different initiatives throughout the health and social welfare sectors focusing on user/customer/consumer involvement/engagement/participation. These have arisen in a number of different, albeit overlapping, ways, drawing on different traditions and combinations of circumstance. In some instances they have arisen as a result of intense advocacy by social movements formed by service users and/or their families and carers, for example in the fields of mental health, aged care, disability and women’s health (Curtis and Taket 1996; Postle et al. 2005), although it should be noted that some identify the importance of policy failures in creating a climate in which attentiveness to consumer perspectives increased (Tomes 2006).
The HIV/AIDS pandemic saw the rise of a social movement around HIV/AIDS activism, and the use of rights-based approaches, something that was also developing in response to the challenge of poverty and achieving appropriate inclusive development (Taket 2012). Other traditions arose, labelled ‘action research’ and ‘participatory research’, and then later a whole tradition labelled ‘community-based participatory research’, and these are discussed in a later section of this chapter.

In this chapter we now provide an overview of current social inclusion practice in five different sections, focusing in turn on policy, service design, service delivery, community life, and finally research. These sections examine practice around the globe as well as introduce the specific exemplars that form the basis of the chapters in Parts 2 to 6 of this book.

Our consideration of socially inclusive practice in this book has an international focus; contributing chapters represent a range of countries in addition to Australia. In addition, this introductory chapter locates our discussion firmly within a global context by including literature and examples from around the world. Although published formal academic research is dominated by that from high-income countries, there are many excellent exemplars of inclusionary practice from low- and middle-income countries, and indeed important roots of different traditions in such practice lie in precisely these countries.

It is important to recognise that, in a single book, we cannot be comprehensive in our coverage of everything, which is why this chapter is titled ‘Scoping Social Inclusion Practice’. We also recognise that inclusionary practice and the literature that captures it is growing rapidly, and that research and practice continue to better inform our understandings of how to practice social inclusion. What we have tried to do, therefore, is explore the range and diversity of inclusionary practice that exists.

Practising inclusion in policy

Over the past decade there has been an increasing focus internationally on social exclusion as an indicator of poor health and wellbeing outcomes. Recently, there has been a clear directive to governments, from the WHO Commission on Social Determinants of Health, that social inclusion is their responsibility and needs to be addressed at the policy level (Popay et al. 2008). In this section we explore this issue in three different ways. First, we look at policies that are specifically about social inclusion. Secondly, we consider how policies can be socially inclusive. In other words, how they can serve to promote social inclusion in the domains in which they are concerned. Finally, we look at the question of inclusion in policy making processes.

Policies on social inclusion

Social inclusion policy has historically focused on reducing poverty with a more recent shift to combating exclusion and increasing inclusion in social domains
as well (Atkinson et al. 2005). Where governments have developed and implemented specific policies on social inclusion, these have sought to address past exclusion and its consequences and to promote future inclusion.

Policies on social inclusion developed by the European Union (EU) have served as models on which many countries have based their own policies. In 2005, common EU objectives for social inclusion were agreed, but member states can focus on the policy priorities most relevant to their national context (Commission of the European Communities 2005). Some critics, for example Daly (2007), have argued that this represents a lessening of the priority given to challenging social exclusion.

Table 1.1 provides an overview of the areas covered in the EU social inclusion policy in comparison to selected country-level policies. It should be noted that the list of areas covered in European social inclusion policies continues to develop; this ongoing commitment is demonstrated in the Europe 2020 Strategy, which includes specific attention to social policy aimed at improving social inclusion (Social Protection Committee 2011).

Outside of Europe there has also been a growing focus on social inclusion policy. However, as evident in Table 1.1, despite the United States, Mexico and China having adopted social inclusion policies, they lag behind Europe in terms of scope and coverage. In these countries social inclusion policies are predominantly focused on anti-poverty approaches, lacking the coverage of the broader social determinants of poverty. For example, Silver and Miller (2003) argue that the United States’ thinking in regards to social policy is dominated by the ‘poverty-line’, individualism, discrete programmes, single-focused policies, disjointed approaches and a narrowing of the scope of welfare provision. Boushey et al. (2007) argue that the concept of social inclusion needs to move beyond America’s limited poverty-based definition to a focus on creating policy that provides ‘an inequality-based understanding of income and well-being, and builds[... understandings of social issues by naming a phenomenon that isn’t adequately identified in the United States by existing terms’ (Boushey et al. 2007: 4). Similarly, ‘Vivir Mejor’ (Live Better), Mexico’s national social inclusion policy, developed in response to the financial crisis in 2008 (Global Extension of Social Security n.d.), is predominantly concerned with addressing poverty, labour force participation, and disparities in income and education.

Local area policies on social inclusion have been adopted within some countries, in some cases preceding national initiatives. For example, prior to 2007, when social inclusion became a key focus of national social policy in Australia, South Australia had adopted policies on social inclusion despite there being no national policy directive (Government of South Australia 2004, 2007). Similarly, some Canadian provinces have developed their own provincial-level policy in the absence of a national policy on social inclusion in Canada, although a report on the development of a national social inclusion policy is due to be released in December 2012 (Ogilvie 2012).

As Table 1.1 shows, a commonality across these policies on social inclusion is the focus on service provision. All the policies highlighted here have explicitly
Table 1.1 A summary of selected policies on social inclusion at the regional and country level

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<thead>
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<th>Scope</th>
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<th>UK</th>
<th>Ireland</th>
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Sources:
- d Australian Government (n.d.)
- e Bromell and Hyland (2007)
- f Boushey et al. (2007)
- g Global Extension of Social Security (n.d.)
targeted social, health or welfare services in order to address and combat social exclusion and improve social inclusion. Even though governments and international bodies may have positive intentions and aspirations in relation to social inclusion policy, and despite the importance of national and state-level frameworks, competing demands for finite resources means policy ends up being compromised. Thus policies may have increasing applicability to the broader population, but potentially fail to meet the needs of those most excluded.

**Socially inclusive policies**

While policies on social inclusion at regional or national levels indicate commitment to improving the lives of the general public with specific targeting of those most at risk of exclusion, it is often argued that all policy should be socially inclusive (Popay et al. 2008). All policy should incorporate the principles of justice, equity and fairness, avoiding excluding particular socio-demographic population groups defined by characteristics such as gender, beliefs, culture, ethnicity, religion, or (dis)ability. The importance of socially inclusive policies was recognised by the EU in the development and implementation of the agreed social indicators and National Action Plan on Social Inclusion. However, evaluations of the social inclusion framework have demonstrated that these values have not underpinned the development of all EU policy (Cancedda and McDonald 2011). In Chapter 4, Crisp and Ross consider the issue of socially inclusive occupational health and safety policy for sex workers. Although occupational health and safety policy is intended to provide workplace protection to all workers regardless of occupation, Crisp and Ross demonstrate its frequent failure to do so in the case of commercial sex workers. They argue that policies and practices which actively promote protection, rather than regulate unsafe behaviours, are not only more socially inclusive but also more effective.

Mental health is one area where considerable effort has been undertaken to ensure policies are inclusive. For example, England’s National Social Inclusion Programme aims to inform and implement inclusive policy in the area of mental health, including community engagement, employment, education, housing, arts and culture, and leadership and workforce (National Social Inclusion Programme 2009). Similarly, mental health policy in Australia is concerned with education, housing and employment of those who experience poor mental health, and specifically aims to implement policy that is inclusive (Commonwealth of Australia 2008).

In 2009, the Australian Federal Government launched the Australian Public Service Social Inclusion Policy Design and Delivery Toolkit. The purpose of this toolkit was to provide an approach for the design and delivery of socially inclusive policy. The toolkit covers both policies designed primarily to meet the needs of the whole population and those that are focused on meeting the needs of specific disadvantaged groups (Australian Government 2009). This was claimed to be a fundamental shift in the way all major policies were designed and delivered by recognising the need for all policy to be socially inclusive.
Scoping social inclusion practice

From health to education through to infrastructure, the law, financial services and other economic areas (Australian Government 2009: 1). Similarly, New Zealand has developed a step-by-step checklist for policy development or service delivery planning to work towards socially inclusive policy and practice (Bromell and Hyland 2007).

However, national guidelines for inclusive policy do not necessarily result in local or regional policies that are socially inclusive. Layton and Wilson (Chapter 3) demonstrate this point when they discuss requirements for effective policy in the area of disability, drawing on the Victorian Aids and Equipment Programme which provides assistive technology in the state of Victoria in Australia. The authors posit that effective policy should be based on the principles of human rights, equity, and capability to promote inclusion rather than a rationing approach, which only serves to perpetuate social exclusion for those who are already marginalised.

Given the complexities and difficulties in designing and enacting truly socially inclusive policy, there can be a tendency for policy makers to ascribe exclusion to individuals’ problematised behaviours rather than to problematic social structures and relations (Bacchi 2007); for example, government approaches to illicit drug use (Bletsas 2007). In Chapter 2, Barter-Godfrey and Shelley discuss the issue of conscience clauses in health policy, with a particular focus on reproductive health. They point out the challenges posed by trying to find appropriate policy solutions that respect the individual values of professional staff while at the same time not compromising the delivery of services to different population groups.

Inclusion in policy making

Perhaps one of the most basic and integral aspects of social inclusion in regards to policy is public participation in the policy making process. Without participatory policy development one has to question whether or not any policy can be fully inclusive. As discussed earlier, Arnstein’s ladder of citizen participation (see Figure 1.1) offers a continuum of public participation from the least participatory to the most inclusive. The Universal Declaration of Human Rights (UN 1948) and the International Covenant on Civil and Political Rights (UN 1966) both make explicit references to one’s right to participation in civil activities and decision-making processes. Public or citizen participation is a right that aims to involve those potentially affected by or interested in a decision. Thereby, those who may be affected by a decision have a right to be involved in the decision-making process with the view that their involvement will influence the decision-making process and outcome.

In 2001, the Organisation for Economic Co-operation and Development (OECD) released ten guiding principles for open (transparent, accessible and responsive) and inclusive (inclusion of diverse citizens’ voices) policy making designed to assist governments in strengthening their policy performance and service delivery. After evaluation and review, these ten guiding principles were
updated in 2009 and now include: commitment; rights; clarity; time; inclusion; resources; coordination; accountability; evaluation; and active citizenship (OECD 2009).

A commitment to inclusive policy making is found in many countries, including Australia, Canada, France, Germany, New Zealand and the UK (OECD 2009). For example, inclusive policy making has been demonstrated in Wales as a way of interrogating policies and practices to ensure that consideration is given to ‘advancing equality of opportunity, eliminating discrimination, harassment or victimisation, and promoting good relations’ (Welsh Assembly Government 2010: 1).

One population for whom considerable attention has been given to inclusive policy making is young people. The United Nations Convention on the Rights of the Child, which came into effect in 1990, promotes the rights of young people, including their right to participate in all decisions that affect them (UN 1989). The inclusion of young people in policy decision-making is now firmly on government agendas internationally. However, it has been argued that this engagement with young people has been primarily around youth-centred issues rather than broader issues of public significance such as housing and transport (Tisdall et al. 2008). Further to this, the extent to and ways in which young people have been engaged in policy making have varied considerably. Vromen and Collin (2010) provide an interesting Australian-based analysis of the ways in which young people have been and can be engaged in policy making from the perspectives of young people themselves in addition to those of policy makers. They highlight conflicting views between the policy makers and young people, with young people arguing for less formalised ways of contributing than those being offered by policy makers. Similarly, Macpherson (2008) argues that, while the social exclusion policy agenda in the UK has incorporated active participation for young people, the focus of this participation has tended to be on ‘reducing problematic behaviour rather than exploring positive engagement of young people in decision-making settings’ (Macpherson 2008: 361).

Practising inclusion in service design

We turn now to inclusion in service design, covering the different fields within health and welfare services, and highlighting some of the key factors behind successful inclusion in design. Calls for inclusion in health and welfare service decision-making are found at international, national and local levels, and WHO (2003) identifies this as an essential ingredient of democratic and accountable health systems. The Global Standards for the Education and Training of the Social Work Profession note the importance of the ‘involvement of service users in the planning and delivery of programmes’ (IASSW and IFSW 2004: 5). Examples of the way this has been taken up nationally in different contexts are provided in Table 1.2. We now examine practising inclusion in service design in terms of overall governance, followed by specific services, and then inclusive envi-
rnonments and universal design. The chapters within Part 3 of the book are all exemplars on inclusion in the design of specific services, and are introduced within that section below.

**Overall governance**

Despite the proliferation of different organisational structures and processes implemented in different places to include service users and/or carers within the overall governance structures of health and social welfare services, there is only a limited amount of research that has examined the experience of the service users and/or carers involved. In the research that exists, two different types of governance structure can be distinguished. The first uses a wide variety of different kinds of representative structures, some elected, some not, but all

**Table 1.2** Contrasts in mandates for inclusion in service design

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<th>Country</th>
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<td>UK</td>
<td>• <em>Local Voices</em>, national policy initiative (NHS Management Executive 1992)&lt;br&gt; • National Health Service (NHS) Plan (HMG 2000)&lt;br&gt; • NHS Cancer Plan (DoH 2000) set a specific target that by 2001 cancer networks should take account of the views of patients and carers when planning services. This represented a considerable challenge, given the findings of a study by Gott et al. (2000) published in the same year as the cancer plan. Gott et al. (2000) found that, although user involvement was seen as important by both cancer service users and staff, there were significant differences in views on the scope of involvement and who should be involved. They also found considerable suspicion and hostility between users and service staff.&lt;br&gt; • NHS-related legislation: Section 11 of the Health and Social Care Act 2001 (HMG 2001); and the NHS Reform and Health Care Professions Act 2002 (HMG 2002)</td>
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<td>Scotland</td>
<td>• <em>Patient Focus and Public Involvement (PFPI)</em> policy initiative (Scottish Executive 2001, 2004)&lt;br&gt; • Statutory requirement for direct involvement of patients and the public for NHS Boards (Scotland Bill 2004). This applies to all levels, understood to range from individual care planning up to major service redesign. Steps were also taken to ensure monitoring of progress.&lt;br&gt; • Reporting requirements for Boards – yearly using a Patient Focus and Public Involvement (PFPI) self-assessment framework (Scottish Health Council Workplan 2006). Scottish Health Council, established in April 2005, responsible for monitoring achievements against PFPI performance standards jointly with Quality Improvement Scotland.</td>
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essentially working within a framework based on inclusion of representatives within traditional meeting or committee processes. In contrast, the second is where a variety of different ways of eliciting views – involving separate structures or processes – is used with the resultant views then fed into the planning/design process. The first type of structure has been associated with only limited success, and with a wide range of barriers and constraints, while the second has yielded more promising outcomes. A number of specific studies are considered below.

Milewa et al. (2002) studied NHS primary care groups and trusts in three districts in the UK to explore perceptions about partnerships for involvement. They found that managers and health professionals exercised considerable influence in comparison to patients and citizens; however, in the variation across the three districts studied, they identified some potential for increased lay influence through the development of advocacy coalitions. North and Werkö (2002) also examined consultative and participative processes in primary care groups/trusts in England, comparing them to the local budget holders for health services in Sweden, local councils and municipalities. Based on a review of the literature, they identified considerable activity among English NHS primary care groups and trusts; positive outcomes from this were often not present or were not known, and they concluded that participation is limited to consultation. In Sweden, initiatives were more limited in number to just a few councils. One distinctive approach in Sweden was the use of study circles (created using already existing adult education networks that are supported by government grants) to debate healthcare matters and to feed into deliberative processes. In the counties using this approach some 3–5 per cent of the total population participated, although those participating were not a representative group: older people and women were over-represented. In only one Swedish local council was there sustained channelling and use of citizens’ views as a result of this approach. Important factors identified by North and Werkö as underlying these findings included political cultures, institutional arrangements, and the complexities in healthcare planning. Neither of these studies included any detailed examination of the experience of those participating or outcomes for participants.

Coad et al. (2008) presented a limited evaluation, based on a single workshop, of the working of a youth council at an acute hospital trust in the UK. The council consisted of a diverse group of 17 young people (aged 11–18 years), who contributed to a wide range of design activities in connection with hospital services and related research. The council was facilitated by the trust’s Patient and Public Involvement facilitator, as was the evaluation workshop. Youth council members reported increases in self-esteem and confidence, and contrasted the way they felt taken seriously in the youth council compared to in society at large. The role of the facilitator was identified as particularly important in the positive outcomes reported.

Brooks (2008) explored a patient and public council created within an acute hospital in the UK. The council was set up by senior nursing staff as part of a
Locally initiated patient and public participation strategy. The study identified a number of tensions created as council members attempted to get their own issues onto the agenda but were resisted by the (nursing) chair of the council. There were also initial difficulties in the relationship between nursing staff and council members. Interestingly, it was the inclusion of a rather different type of process (based on a recommendation from the research team) that allowed council members to narrate their own experiences and use these as a basis for building a future agenda for action that significantly impacted on nursing staff views. Brooks (2008) concluded that real change, consequent on participation through means such as a council, requires change in the expectations of professionals about their relationship with service users. Similarly, Leung (2008), studying welfare organisations in Hong Kong with varied client groups, including older people, people with mental health issues, families, young people, drug abusers, and people with visual impairment, identified service providers’ discomfort with the discourse of accountability to the service user. He concluded:

the institutional inclusion of welfare service users into a discursive space is a necessary but not sufficient condition for the realization of a mandate of accountability to the welfare service users, unless the power dynamics in the due process of the users’ involvement is properly confronted.

(Leung 2008: 543–4)

Farmer et al. (2010), exploring barriers to the inclusion of older people’s views in service design in remote rural Scotland, expressed a closely related conclusion in identifying:

tensions that result from a misfit between the way communities live and the ideology and methods driving management and policy making. If the voices of local people are to truly be incorporated in service design, then the first step is to acknowledge that rural citizens have a distinct and legitimate perspective that aligns with their desire for quality of life in sustainable communities.

(Farmer et al. 2010: 282)

Finally, in terms of more recent studies examining various forms of governance boards, Chessie (2009) explored the early experience of citizen governance boards in Canada’s health service, and Gauld (2010) explored elected district health boards in New Zealand. Chessie found the Canadian boards deficient in ‘real’ engagement (understood as reaching the upper levels of Arne-stin’s ladder), and Gauld identified problems including: low voter turnout; failure to achieve minority representation; and constraints affecting the ability to achieve representation of different communities. Gauld concluded that boards have only a limited role to play in promoting participation, and need to be supplemented with other methods.
We now turn to examples that worked with diverse ways of eliciting involvement, illustrating the very diverse range of methods that can be used to foster inclusion in service design. Firstly, Nimegeer et al. (2011), drawing on work trialled in remote areas in Scotland, reported on the use of a planning ‘game’ that uses a number of types of cards to allow community members to express priorities and design preferences in a way that is directly usable by health service managers. The game combines the priorities of the community (including their experiences of using services) with existing service data. It can be used by groups of community members alone or mixed groups of community members and service managers. Their study of using this resource in different ways led them to conclude that the game needs to be embedded in ongoing processes. A game was also successfully used as a method of involvement with service users with serious mental illness in a residential service setting in the UK to elicit their views on the design and refurbishment of their environment (Fitzgerald et al. 2011), and concluded:

The serious game format enabled the bridging of significant barriers to service user involvement because of its flexibility, inclusivity and familiarity. As a result, this paper recommends it as a meaningful, useful and fun way to engage services users in potentially threatening, complicated and possibly boring service development.

(Fitzgerald et al. 2011: 322)

Fletcher et al. (2011) describes a study into the views and experiences of children and young people with regard to hospitals that was carried out as part of an ongoing commitment to the reconfiguration of children’s services and the development of a new undergraduate children’s nursing programme in the south of England. The use of a draw and write/tell technique successfully involved children from pre-school age upwards. Murray (2012) discusses the Disabled Children and Young People’s Participation Project that was established by Barnados (Northern Ireland) in 2002 to explore ways of involving children and young people with disabilities in decision-making processes within Children’s Services Planning of the Health and Social Services Board. Over 200 young people have participated in its ten years of existence. Participation is via peer group workshops or one-to-one activities, and there is also a project advocacy group. Communication involves specialist information technology (IT), music, drama and digital media, and those who have been successfully involved report empowerment. Murray notes that there are significant requirements for both resources and facilitation to enable these outcomes.

**Inclusion in specific services**

Another avenue for inclusion in service design is at the level of specific services, and, as already noted, mental health, cancer, HIV/AIDS and disability are all areas where a wide variety of different initiatives exist. The successful examples
that exist demonstrate that inclusion can be achieved with a variety of different groups of people who have traditionally been excluded. As with the preceding section, the most successful inclusion initiatives are those based on diverse methods that move away from ‘representation’ or membership at meetings or in committee structures.

In relation to mental health services, the social movements created by service users and carers have resulted in the adoption of formal mechanisms for inclusion in many places. In Australia, 2002 data showed some type of formal mechanism to incorporate consumers’ views was in place in 89 per cent of mental health services, and consumers or carers were present in local executive decision-making structures in 61 per cent of services (DOHA 2004; Whiteford and Buckingham 2005). One form of involvement is as a ‘consumer consultant’, which has been used successfully in Australia, and for a much wider range of functions than solely service design (Middleton et al. 2004). In New Zealand, Gawith and Abrams (2006) reported that consumers and carers were active in contributing to strategy, policy and service development, both nationally and locally. Such increasing opportunities for inclusion, be it advocacy, advice or input, in service provision have not been without challenges, including resourcing, staff resistance and user representativeness, as Whiteford and Buckingham (2005) demonstrated in Australia, Crawford et al. (2003) in the UK, and Mowbray et al. (1998) in the USA.

In terms of successful initiatives, Janzen et al. (2006) described a longitudinal study of four mental health consumer-run self-help organisations in Canada. They found staff and members of the four Consumer/Survivor Initiatives had participated actively in system-level activities, including community planning, public education, advocacy, and action research. These activities had some important outcomes: perceptions of the public and mental health professionals about mental health or mental illness improved; and, there were positive changes in service delivery practice, service planning, public policy, and funding allocations.

The Californian mental health system’s use of stakeholder-driven planning was explored by Cashin et al. (2008), based on an analysis of 141 programmes in 12 county community services and support plans. They concluded that the innovative approaches to recovery-oriented services generated successfully involved consumers and family members in service planning and delivery, as well as building community partnerships that have created new opportunities for consumers to meet their recovery goals. Mechanisms used included paid and board positions, as well as attention to improving cultural competency in the workforce, and strategies for community collaboration. They noted the diversity in strategies they found, and concluded that this diversity is required.

The experience of a group of mental health service users in Northern Ireland involved in the Public Initiative for the Prevention of Suicide – Greater Shankill Bereaved Families Rights Group, supported by the Participation and the Practice of Rights Project is analysed by McMillan et al. (2009). Policy change was advocated for using a human-rights-based approach that empowered participants. A participatory, ‘bottom-up’ approach was used to set human
rights indicators and benchmarks defined by group members themselves. Focusing on just one issue, follow-up care, McMillan et al. (2009) demonstrated how the group was able to bring about change on this issue across Northern Ireland. This was done through the implementation of a simple service innovation, a card on discharge containing details of the next appointment, which enhanced service users’ feelings of connection to services. McMillan et al. emphasise the range of activities the group undertook in order to achieve this change and, in particular, how the group worked outside the existing government–designed consultative structures that were regarded as unable to deliver change. This brings us to an important finding that reoccurs across much of the research, namely that flexibility in methods and processes of involvement is extremely important in ensuring that diverse groups are enabled to be included, as the work considered next also illustrates.

The Delphi method is a process that facilitates group consultation, with the aim of finding common agreement between experts, on topics of uncertainty (Rowe and Wright 1999; Hasson et al. 2000; Meyrick 2003; Okoli and Pawlowski 2004). The process is carried out over a number of rounds; after each round, results are summarised and fed back for further elaboration of views, aiming to identify, by the end of the process, statements expressing areas of consensus and areas about which there is no consensus. Delphi methods have proved useful in a range of settings, bringing together the views of ‘experts by experience’ with ‘experts by profession’ around various design tasks, for example: the development of guidelines for caregivers of people with bipolar disorder (Berk et al. 2011); and therapeutic and treatment interventions for domestic and sexual violence and abuse (Itzin et al. 2010a, 2010b). The methods have the advantage of being able to place the different sources of expertise on an equal footing through the anonymity of feedback in the different rounds. In some cases the method has been used with users alone; for example, Estathiou et al. (2008) explored health care users’ priorities for cancer care in Greece.

Yet another example of innovative methods is found in Burgess-Allen and Owen-Smith’s (2010) study of local alcohol service review in England. They compared mind mapping with traditional thematic analysis, and their findings suggest that the use of a mind mapping approach to managing qualitative data can help achieve meaningful participation from service users and families in situations characterised by limited resources.

Hubbard et al. (2007) reviewed 28 studies of involvement of people affected by cancer in UK policy and planning, highlighting resources and changes in attitudes as prerequisites. While 12 studies claimed success in terms of positive impact on policy and planning, this was based on perceptions of those involved rather than any other evidence in 11 out of the 12 studies. Six studies reported positive effects of involvement on the people with cancer, including empowerment and finding the experience personally therapeutic. However, most of the studies reported a limited socio-demographic range of people involved, excluding key groups such as people who are socially deprived, minority ethnic groups, older people and younger people.
In relation to services for drugs and alcohol, three comparatively recent studies, two in Australia (Bryant et al. 2008a; Treloar et al. 2011) and one in Ireland (King 2011), found relatively limited achievement in terms of effective inclusion. Bryant et al. (2008a) reported that, although consumer participation activities were not uncommon in Australian drug treatment services, existing activities were largely low-involvement activities, or activities concerned with providing information to or receiving information from consumers. They also reported that consumers largely lacked knowledge of participation opportunities, and many were unaware of complaints systems. In analysing the reasons lying behind the disappointing results, both Treloar et al. (2011) and King (2011) identified problems with resourcing the initiatives adequately and the need for education and training for all involved, plus, importantly, attitude change on the part of professionals involved.

All three of the chapters in Part 3 on Practising Inclusion in Service Design take place within specific services and they all illustrate the use of new forms of information and communication technology to support inclusion in different ways. In Chapter 5 Pollock and Taket describe how flexibility in use of methods was necessary to ensure each individual service user in three very diverse service groups had a real opportunity to participate. In Chapter 6, Stagnitti et al. describe the variety of processes and new ways of working introduced into the primary school setting that helped foster inclusion, including the use of Kaizen groups (student leadership groups), based on ideas that originated in Toyota’s drive for worker involvement in quality improvement (English and Hill 1994). Finally, in Chapter 7, Goldingay and Stagnitti describe how inclusive service design for young people with learning disabilities who exhibit behaviours of concern can be achieved through the use of innovative play-based approaches.

Inclusive environments and universal design

One important part of service design is the physical environment in which services are delivered or activities take place, including a wide range of community-based facilities and settings, as well as individuals’ homes. The notion of universal design, the adoption of design practice that emphasises designing for use by diverse users, also serves to reduce resource requirements at a later stage to accommodate inclusion of diverse groups in terms of access to, and use of, particular spaces and facilities. Accessibility of facilities from which services are provided remains a key challenge to promoting inclusion. Buildings that require special adaptation to accommodate diverse users, and where these adaptations result in separated zones and entrances, are stigmatising and foster exclusion. Universal design represents an attempt by the design community to start with the notion of designing for diversity and to move away from copying accessibility features from codes, guidelines, and standards. This latter practice often results in ‘code minimums’ being applied in a manner that is separate and different from ‘normal’ design, and is not really ‘equal’.
The Center for Universal Design (1997) sets out seven principles for universal design:

1. Provide equitable use.
2. Flexibility in use.
3. Simple, intuitive use.
5. Provide tolerance for error.
6. Require low physical effort.
7. Size and space for approach and use.

Catlin (2008) described the use of intensive design events (charrettes) involving members of the disability community in Chicago, as well as experts by profession (architects and accessibility). Catlin (2008) also identified that universal design need not cost more in terms of building products. Crews and Zavotka (2006), using literature from the USA and other high-income countries, explored the value of universal design in meeting the needs of the growing numbers of frail elders living in the community, and enabling them to remain in the community for far longer, without the need to move home. Price et al. (2004) presented an interesting case study of a state-wide community education programme on universal design in Ohio. In this, the collaborative partnerships achieved between educators, outreach professionals, students, and a community retail chain succeeded in raising both interest in and awareness of universal design changes that enabled older adults to age in place.

The notion of universal design applies to products as well as the built environment. De Couvreur and Goossens (2011) considered how community-based rehabilitation provides a useful context for innovative design of assistive technology by users and therapists, which can be shared increasingly easily through the internet to allow others to benefit also. They point out the possibilities of the internet assisting in getting designs manufactured, and discuss different cases of 'co-design', where clients with disabilities work in a team with a caregiver, a student of industrial design and a student of occupational therapy (and others as appropriate) to design and make something that helps the person with a disability in an activity of personal value to them. They describe how a 'design for (every) one' framework can support such co-design projects using case studies from Belgium and The Netherlands.

There are a number of examples where universal design has been used to promote social inclusion, including in higher education in Australia (for example, Hitch et al. 2011), accessibility for people with disabilities in New York (Myhill et al. 2008) and services for older adults in Texas (Dumbaugh 2008). Dumbaugh conducted a literature review of the older adults' travel-related needs, abilities and preferences in order to move beyond the inevitable segregation that occurs for older adults (Dumbaugh 2008). The importance of the notion of universal design is clearly illustrated by Taket et al. in Chapter 11 in terms of the isolation faced by frail older people in the community brought
about by lack of mobility, influenced strongly by the built environments in which they live.

Practising inclusion in service delivery

Staff attitudes and knowledge have often been identified as a barrier to achieving inclusion in service design, and different ways of addressing this have been identified. We first consider the literature on various forms of inclusive professional practice. Following that, we consider involvement of service users in training and education, and one approach towards addressing the barriers posed by staff attitudes and knowledge. A second approach seeks to include service users as employees within the system in specially designated posts, and this is also considered below.

While a service can be designed using inclusive principles, how it is delivered is crucial. There has been a proliferation of different terms used to refer to such inclusive practice. Within disability services and occupational therapy, terms such as person-centred approach, person-centred care, person-centred practice and person-centred support have been used, with yet a further set of variants with the word ‘client’ replacing ‘person’ (for example: McCormack and Collins 2010; Carnaby et al. 2011).

Anti-oppressive practice

There is an extensive literature on providing services in an inclusive manner, which is sometimes described as ‘emancipatory practice’, ‘human rights practice’, ‘anti-discriminatory practice’ and/or ‘anti-oppressive practice’ (Cemlyn 2008). Much of this literature has emerged from social work in the UK (Wilson and Beresford 2000; McLaughlin 2005) and predominantly involves practitioners working with individuals and communities who are the most marginalised members of society (Lavalette and Mooney 2000). Such an approach begins with the acknowledgement that individuals or groups are marginalised:

An anti-oppressive practice model . . . examines differences used to set apart individuals or groups from one another. The people or group become excluded and marginalized by the dominant society that benefits from the group depicted as undesirable.

(Hines 2012: 24)

Hence, anti-oppressive practice begins with the recognition that service users may have experienced oppression as a result of individual, organisational, cultural or social factors, which limits their ability to realise their full potential. Consequently, rather than reinforce existing sources of oppression, practitioners may need to advocate for, and challenge this oppression on behalf of, and in conjunction with, service users. This in turn requires practitioners to recognise the power imbalances between themselves and service users and seek to
implement joint decision-making processes as to what responses should be undertaken to enhance wellbeing for the service user (Hines 2012). Nevertheless, it is important that practitioners do not ‘perpetrate just what they are trying to avoid: grouping, sorting and “othering” marginalized individuals rather than listening carefully to what diverse, intersecting groups of individuals within their multiple communities identify as central issues and priorities’ (Hudson 2012: 168). It is also critical that professionals recognise the limits of joint decision-making, for example when working with involuntary clients, including those with mental health issues who may be subject to legally mandated treatment orders (Campbell and Davidson 2009). There is a tension that needs to be negotiated, however, in ensuring that joint decision-making does not derogate from the professional’s responsibility for assessing and managing risks while also clearly respecting the preferences of individuals, carers and families (Alaszewski 1999; Morgan and Hemming 1999; Munro 2010).

As mentioned previously, in many areas of health and welfare practice, there has been a growing recognition of the need for client or service user participation in decisions which affect them. However, as Furlong describes in Chapter 8, the relationship between service users and professionals is critical, and needs to be characterised by practitioners respecting and promoting the agency of those they are working with, and supporting them when they make courageous decisions. Nevertheless, this does not mean professionals can take a passive role. Those they work with may be unaware of the oppression or exclusion they are experiencing, or may be aware of it but have no idea as to how it can be challenged. Therefore, getting service users to the point at which they can engage in joint decision-making may require extensive preparation (Hines 2012).

Anti-oppressive practice challenges traditional paradigms that emphasise differences and boundaries between practitioners and those they work with (Martínez-Brawley and Zorita 2011). In her analysis of interviews with ten Canadian social workers, Hillock (2012) concluded that workers who identify themselves as ‘other’ are more likely to be able to identify experiences of oppression in the narratives of those they work with. Rather than being detached objective observers of social phenomena, Strier and Binyamin have argued that Israeli anti-poverty services

... must be staffed by workers capable of developing emotional, intellectual and moral involvement with issues of poverty. The principle of involvement implies working at high levels of intensity, acting under conditions of ambiguity for extended periods of time and persevering even if there are no quick results.

(Strier and Binyamin 2010: 1919)

Working with the most marginalised members of the community is frequently emotionally exhausting and demoralising. In addition to receiving adequate personal support, an important mechanism to retain practitioners working in an anti-oppressive framework is legitimising, within their job
descriptions, the challenging of policies that marginalise segments of the populations (Jones 2012). Without such a commitment to promoting human rights, anti-oppressive practice can readily become tokenistic (Wilson and Beresford 2000; Cemlyn 2008) or merely aspirational (Hines 2012). Sung-Chan and Yuen-Tsang (2007) have discussed that, even though a group of Chinese social work students moved from identifying the problems of unemployed women as due to individual deficits, to recognising societal factors which contributed to their unemployment, actively redressing these societal factors did not necessarily occur.

While a focus on interpersonal relationships is a necessary component of anti-oppressive practice, it remains necessary for the structural inequalities that marginalise individuals and groups to be challenged (McLaughlin 2005). Rather than assuming issues are due to deficiencies in an individual which can be remedied by some form of intervention, anti-oppressive practice recognises the strengths of individuals and communities and seeks to explore how these can be used to challenge structural inequalities that underpin the need for services (Strier and Binyamin 2010). Hence, in addition to working with individuals, empowerment of service users may be further enhanced through facilitation of groups which provide social support and encouragement for members of excluded groups to gain strength to challenge their exclusion (Hines 2012). Lennon et al. provide an example of this in Chapter 10 when they describe a community service organisation in Australia that supports sex workers and aims to build their sense of social connectedness.

Working as an anti-oppressive practitioner requires skills in critical analysis. Additionally, it has been suggested that a ‘... critical and informed focus on human rights can be a further potentially powerful tool ... in seeking to contribute to resistance to oppression, collective solidarity and the promotion of emancipatory change’ (Cemlyn 2008: 238). Nevertheless, the effectiveness of an anti-oppressive approach on its own may be insufficient in multicultural communities, and there is a growing awareness of the need for practitioners to be culturally competent (Cemlyn 2008). Makhoul et al. make this point in Chapter 9 in their case study involving psychotherapy in Lebanon with individuals whose sexual orientation or identity is other than heterosexual. Cultural competence has been raised as an issue both in pre-qualifying education in the UK (Parrott 2009) and in ongoing professional development of qualified workers in New Zealand (Hair and O’Donoghue 2009).

**Inclusion in the workforce**

Inclusion of marginalised or disadvantaged groups in the health and social welfare workforce has been viewed as a route to increasing inclusion in the domain of service use, and to increasing the accessibility and acceptability of services to such groups. This has particularly been the case in terms of mental health services (Cleary et al. 2011; Ostrow and Adams 2012), but is also found in other health and social welfare services, such as services for people with disabilities
Inclusion in the workforce into specially designated posts (rather than participation in workforce in the usual range of professional roles) has received particular attention. The names given to such positions/post-holders vary considerably: peer worker, lay worker, user advocate, expert by experience, peer support specialist. As McLaughlin (2009) demonstrates, many, if not all, of these terms can be problematic and unable to do justice to the complexities of the relationships involved; a consequence of this, we argue, is the need for those involved to reflect critically on the terms in use and whether they are satisfied with the positionings implied by their use or whether they should be changed. As yet, there is only limited research exploring the experiences of people in this group. Mowbray et al. (1998) explored success in extending involvement into service provider roles, and identified the wide range of benefits this can bring, although emphasising that careful preparation is necessary to bring these about. In the UK, the Commission for Social Care Inspection (CSCI), now the Care Quality Commission, has developed an extensive ‘experts by experience’ initiative within its functions (CSCI 2007a; CSCI 2009). CSCI’s own evaluations of the use of ‘experts by experience’ in inspections of care homes (CSCI 2007b) and domiciliary care (CSCI, 2007b) provided strong endorsement for their inclusion, although some, for example Scourfield (2010), have questioned whether the experts by experience have found their involvement to be empowering. Cook and Wills (2012), researching lay health trainers in the UK, found they experienced a considerable amount of ambiguity in their role, and they had more autonomy and success in engaging the community when they were located in organisations more embedded in the community than within the NHS itself, illustrating the constraints imposed by the governance context.
Training and education

Repper and Breeze's (2007) systematic review of service user participation in organisational development in healthcare identified 38 different studies examining participation in health worker training; over half of these reported on the initiatives involving mental health service users, but only two reported on carer involvement. Their conclusions highlight a number of studies in which service users found benefits (including increases in confidence, self-worth and empowerment), as well as benefits to students. They also identified the need for careful preparation, support and resources, including remuneration. Five further studies, not included in Repper and Breeze's review, highlight other successful initiatives. Happell and Roper (2003) report on the use of a 'consumer consultant', employed as an academic staff member of the Centre for Psychiatric Nursing Research and Practice in Australia, for training postgraduate psychiatric nursing students. Service users and carers were successfully involved in training mental health workers in the UK (Simpson and House 2002); and in social work education in England (Anghel and Ramon 2009). Fallon et al. (2008) reported on work involving young people in the design of a post registration module entitled 'The Adolescent with Cancer', using methods such as 'Post-it ideas storm' 'diamond ranking' and 'dot voting'. McKeown et al. (2012) looked at service user and carer perspectives on the value of involvement in practitioner education, finding benefits in three different areas: a more positive sense of self; social and relational benefits; and the value of stimulating change.

Arguably the most extensive requirements for service user involvement in professional education are those which were mandated for providers of social work education in England. These specify that service users should be involved in all aspects of social work education, including selection of students, curriculum design, preparation for practice learning placements, provision of placements, and assessment of students and quality assurance, in addition to being involved in teaching. However the means by which this should occur was not specified (Levin 2004). For example, in respect of selection of students, three-quarters of social work education providers involved service users in some aspect of student selection in 2004–5, ranging from roles not involving direct contact with applicants, such as devising the interview schedule and shortlisting of applicants, to having direct contact with applicants, such as participation in selection interviews (Manthorpe et al. 2010). Service user participation in assessment has also varied, and this much more likely to occur in services provided to adults than to children (Moriarty et al. 2010).

Practising inclusion in community life

The health and wellbeing of individuals and groups can be enormously enhanced by their participation in community life (Wenger 1999; CSDH 2008). Community life is not just defined by place of residence; rather, individuals participate in, or identify with, a range of different communities defined by common
interests, activities and/or values. Community life includes social and leisure activities, as well as participation in education, in paid and unpaid work, and through civic participation. Despite the right to participation enshrined in the Universal Declaration of Human Rights and other human rights instruments, the last half-century has seen a number of oppressive regimes worldwide, with associated conditions of corruption, poverty, and lack of participation and voice in political, cultural and social life. This section explores social inclusion and participation in community life, across different contexts and population groups. We do this through examining four different, though overlapping, bodies of work that have addressed social inclusion in the domain of the community life: community development and participatory development; participatory governance; community self-help; and, finally, neighbourhood renewal or regeneration.

Community development and participatory development

There are many definitions of community development, but the basic concept was described by the United Nations, in an early elaboration of article 55 of the charter of the UN, on economic and social progress and development (UN n.d.: para 61): ‘Community Development [is] . . . a process creating conditions of economic and social progress for the whole community with its active participation and the fullest possible reliance upon the community’s initiative’.

Blair (2008) traces the origins of community development to work in India following the conclusion of the Second World War. Community development has been a focus of considerable attention within social work (Ife 2002), health promotion (Minkler 2012) and development practice (Cornwall 2006) globally. Pawar (2009) reviews community development practice throughout Asia and the Pacific, arguing that the four values or principles of human rights, self-reliance, self-determination and participation can provide the basis for effective sustainable community development practice, despite the considerable challenges posed by many socio-political governance systems. O’Leary et al. (2011) provides an overview of the different roots of asset-based approaches to community development, identifying roots in all global regions.

One particularly important influence on community development is found in the work of Paulo Freire, the Brazilian educator, philosopher and theorist. Freire observed those who oppress, ‘exploit . . . and fail to recognize others as persons’ (1990: 41). For over 50 years Freirian education, also sometimes referred to as ‘popular education’, ‘anti-oppressive education’ or ‘empowerment education’, has played a critical role in achieving social change in Latin America (Kane 2001). More recently, Wiggins’ (2011) systematic review of popular education for health promotion and community empowerment found popular education effective in enhancing empowerment and achieving health. However, the relative effectiveness of popular education, compared to traditional education, in increasing health knowledge and changing health-related behaviour remains to be examined (Wiggins 2011).
Participatory development centres on the inclusion of people who are affected by the development process as planners in that process. Arimoto (2012) describes an early participatory rural development programme implemented in Japan in the 1930s that helped foster the adoption of cattle raising and crop diversification. According to Binswanger-Mkhize et al. (2010), Bangladesh and India first implemented programmes that advanced community roles in development in the 1940s. Cornwall (2006) traces a number of different roots of participatory development stretching back into the colonial period. The participatory development approach became widely used in the 1980s and 1990s, arguably as a response to globalisation and neoliberal development policies (Mohan 2001). It was taken up by organisations such as the World Bank (World Bank 1994) and the Asian Development Bank (ADB 1996). The approach is often particularly associated with the work of Robert Chambers and the Institute of Development Studies in the UK (Chambers 1983).

Community development and participatory development have both pioneered the use of a diversity of methods for involving people in matters relating to community life. Rapid Rural Appraisal and Participatory Rural Appraisal (Chambers 1994) represent a family of approaches that draw on insights from Paulo Freire's work, together with that of Orlando Fals-Borda, the Colombian sociologist who was one of the founders of participatory action research, discussed further in the section on research later in this chapter. The emphasis of these approaches is on moving from professionals being 'on top' to professionals being 'on tap', emphasising the importance of professionals acting as facilitators. Action methods refers to a group of different approaches that emphasise diverse ways of exploring and understanding different situations through various forms of action and reflection (rather than just verbal articulation and discussion) with a view to deciding how to change things for the better. Sociodrama (Fox 1987; Sternberg and Garcia 1989) is one US-born tradition, based in Jacob Moreno's psychodramatic approach to psychotherapy (Fox 1987), while Augusto Boal, the Brazilian director, artist and activist, influenced by Freire's work, created the Theatre of the Oppressed to facilitate the identification and investigation of different possible strategies for action (Boal 1998).

Boal's work has also been drawn on in other countries. For example, in the UK, a commissioned report for the Department of Transport, Local Government and the Regions and the Economic and Research Council (ESRC) Cities Initiative identified ongoing inter-ethnic tensions in urban areas, together with a ghettoisation of ethnic minorities into deprived urban areas, and culminating in riots in 2001 (Amin 2002). Amin notes that Boal's Theatre of the Oppressed approach has a key role to play in unravelling deeply held prejudices. He cites examples of effective work in Marseilles, France, and South Yorkshire, England. In particular, enactment of controversial issues enables 'inter-ethnic and intergenerational understanding' (Amin 2002: 14) and is a way to rehumanise those who have been marginalised and excluded. In the USA, Sadler (2010) has used Boal's Theatre of the Oppressed to engage college students in a dialogue about social justice, privilege and equity. She notes that universities struggle to
be truly inclusive of under-represented student groups, an issue considered in Chapter 12 by Crisp and Fox.

The literature on participatory development is extremely large, and views on its desirability and effectiveness vary. Cooke and Kothari (2001), for example, offer a critique of participation as 'the new tyranny' in development thinking, while Hickey and Mohan (2005) offer a very different view, identifying its possibilities for creating social transformation. Participatory development has often been criticised for being tokenistic in the actual levels of participation achieved. There is a smaller but growing literature on the evaluation of participatory development. One particularly helpful review by Gaventa and Barrett (2010) is considered in the concluding section of this chapter. The Asian Development Bank undertook an evaluation study (ADB 2003) of capacity building and participation activities in 22 projects and other activities in 2000 and 2001, concluding that the costs of participation were small compared with the gains.

**Participatory governance**

Both community development and participatory development are usually associated with the most local level in society. However, the notion of participation has also been taken up at other levels, across the entire spectrum from local to national and international. 'Participatory governance' is the term often used to refer to participation across this entire spectrum (Osmani 2008), with others using the term 'participatory democracy', dating particularly from the various programmes and initiatives set up to support development of democracy in Latin and Central America from the mid-1980s onwards (Blair 2008).

Lack of transparency in decision-making, leading to corruption and lack of trust between state officials and citizens, has been identified as a key block to participatory governance (Malena 2009). As a result, Transparency International set up their first Advocacy and Legal Advice Centres in 2003, and now over 50 countries have such centres, including countries in South America and Eastern Europe (Transparency International 2012). These centres have raised citizens' awareness of corruption and assisted them to address it by promoting dialogue between citizens, institutions and government officials (Malena 2009).

The political will (Malena 2009) for both the governors and the governed to engage in dialogue is another key factor in successful participatory governance. Around the world, a number of initiatives have worked to promote such dialogue, but found a number of barriers to doing so. For example, in Tajikistan, local governments were significantly under-resourced following the collapse of the Union of Soviet Socialist Republics (USSR) and subsequent civil conflict (Holloway et al. 2009). Lack of integrity, accountability and transparency were problems identified in work with local civil society organisations in Kenya and Tanzania (Holloway et al. 2009). Strategies to address these problems included improving the motivation of authorities to involve citizens in joint decision-making. To achieve this, effort was made to show how collaboration could benefit those in power, including being voted back into power.
One specific manifestation of participatory governance is the Participatory Budget, a particularly successful example dating from 1989, being that of the city of Porto Alegre in Brazil (Blair 2008). Other examples of this practice have been found in other metropolitan areas such as São Paulo (Hernandez-Medina 2010) and in rural Zimbabwe (Mumvuma 2009). Hernandez-Medina (2010) observed that, in São Paulo, a new way of talking about inclusion in community life has occurred, and now 'participation in decision-making is not only a right, but is also instrumental in achieving greater effectiveness in the implementation of public policies' (Hernandez-Medina 2010: 512). Thus, in São Paulo, Participatory Budgets involve the inclusion of citizens in the production and implementation of public policy, so that decisions are made in the interests of all, especially those experiencing poverty. A similar movement has been noted in rural regions of Zimbawbe, where a number of strategies have been adopted in order to promote 'transparency, accountability and local economic development, as well as improve the well-being of local citizens' (Mumvuma 2009: 159).

The linking of participatory development in particular, and participatory governance more widely, to human rights has occurred in a number of ways, with the use of specifically rights-based approaches to development programming (Jonsson 2003) and debates amongst international development agencies about rights-based approaches and their value (Silva 2003; Nyam-Musembi and Cornwall 2004; Davis 2009). Miller et al. (2005) explore the links between human rights and development, arguing that these have much to learn from each other. In particular, Miller et al. (2005) call for a more holistic understanding of the concepts of power and empowerment and the links between them, arguing this would help to bridge the gaps between development, participation, and rights, and would lead to more effective processes of social change.

Neighbourhood renewal

For many people, one of their key communities is defined by their place of residence, and the importance of the built environment and housing to health and wellbeing cannot be overstated. The existence of enormous geographically patterned inequalities in material resources has led to a variety of initiatives to try and address these, while at the same time promoting social inclusion, health and wellbeing. Sometimes, as in the Healthy Cities movement (Rydin et al. 2012; de Leeuw 2012), this has occurred at the city level, while in other cases, such as neighbourhood renewal (Klein 2004; Thomson et al. 2009) and urban regeneration (Glasson and Wood 2009; Colomb 2011), efforts are concentrated at a much smaller spatial scale, targeting the most disadvantaged localities. The precise composition of such initiatives varies from place to place, but as well as improving the physical environment, social amenities, and employment opportunities, some also aim to increase pride in and sense of community, including feelings of safety and connectedness. A number of jurisdictions have
responded to this through neighbourhood renewal projects, including the UK and Victoria, Australia (Klein 2004; Shield et al. 2011).

The aim of neighbourhood renewal in Australia and the UK is to investigate the complex interrelation between 'local sources of health inequality' and to intervene by 'transforming poor housing, creating employment opportunities, improving education, rejuvenating local economies, reducing crime, and building social capital' (Klein 2004: 110; Neighbourhood Renewal 2010). We note that the term 'neighbourhood renewal' is not always used in this way. In Brussels and Montreal, for example, neighbourhood renewal is considered a process of relatively wealthy groups buying into deprived areas, upgrading the dwellings and hence the social status, and thereby ejecting the more disadvantaged people out of the area (Van Crijkingen and Decroly 2003), a process referred to as 'gentrification' in the UK and Australia. These initiatives are carried out in the interests of those already privileged, and promote further exclusion of those already disadvantaged. They therefore fail to acknowledge and build on the potential capacities inherent within the neighbourhood.

While successful examples of renewal or regeneration schemes do exist, many schemes have been criticised for only achieving tokenistic levels of participation and falling far short in adequately resourcing the community capacity-building required to achieve any more meaningful inclusion that does not perpetuate, or even worsen, social inequities (Jones 2003; Maginn 2007; Agger and Larsen 2009; MacLeavy 2009; van Bortel and Mullins 2009; Pollock and Sharp 2012). The critique offered identifies the importance of recognising the complexity of community life and the power relations within it, as well as how these are constrained by actors and factors outside the community itself, and responding to these in the decision-making and governance processes involved in regeneration (Jones 2003; Taket and Edmans 2003; Agger and Larsen 2009; van Bortel and Mullins 2009; Pollock and Sharp 2012).

**Community self-help**

As mentioned earlier, Freire and others have stressed the importance of enabling disenfranchised citizens to take the initiative to address their oppressive circumstances. One mechanism by which citizens can do so is via community-based self-help and support groups. For example, Kingsnorth et al. (2011) describe a parent peer support group in Toronto, Canada, for parents of children with special care needs. These parents, who were suffering isolation and stress from caring for their teenagers with physical and/or developmental disabilities, initiated the group themselves. Through participation in the group, parents recognised their own expertise, and were able to take some ownership of the processes that affected them. They gained ‘validation and comfort’ (Kingsnorth et al. 2011: 837) from the group that they did not receive from paid professionals, and sought information about participation, inclusion and citizenship. Chapter 14 by Gill et al. also describes a self-help group established by parents of teenagers who have high functioning autistic spectrum disorder
Scoping social inclusion practice

(ASD). This group was set up in response to ongoing isolation experienced by the teenagers, and was inspired by a similar group that one parent had observed on an exchange visit to Sweden. In addition to providing support for these, often isolated, teenagers, the group also acted as a source of support for the parents. Also, in Chapter 13, Hanna and Moore discuss a community-initiated and sustained multicultural women’s friendship group in Melbourne, Australia, which offered peer support and companionship to potentially excluded older women from a range of ethnic groups.

Another example of self-help and support is found amongst people with disabilities in the European Centre for Excellence in Personal Assistance (Mladenov 2012). This movement was initially begun by people with disabilities in America, but spread to Sweden to found the Stockholm Co-operative for Independent Living. Two rallies were organised by this group, one in Bulgaria and one in Strasbourg, to advocate for funding to provide community-based personal care assistants for people with disabilities. Having the funding support to hire personal assistance had a very empowering effect for those receiving these services, as it liberated them to live in the community and empowered them to choose who worked with them and how (Mladenov 2012). A similar emphasis on the need for ongoing financial and political support to ensure the success of self-help initiatives was noted in Germany by Geene et al. (2009), where a preference for decentralised systems at local levels led to a number of self-help initiatives which were supported by professional services.

Practising inclusion in research

In this section we consider the design and execution of socially inclusive research and provide examples of how inclusive research practice can be achieved. As with practising inclusion in the other domains discussed in this chapter, practising inclusion in research means involving under-represented population groups or individuals/communities that are vulnerable, marginalised, or disadvantaged. Within a research context, this also includes groups considered ‘hard to reach’ or groups that are frequently overlooked or omitted from the research agenda, as a consequence of sampling or analysis units chosen. Examples of such groups are: people or communities of a particular ethnicity; older people; children and young people; socio-economically disadvantaged people; people from sexual minorities; people with disabilities; and women without children. This section will consider in more detail why socially inclusive research is important, the practice of inclusion at all stages of the research process, and participatory research approaches.

Why is socially inclusive research important?

In an era of evidence-based practice, rigorous research underpins multiple facets of health and social care practice: it informs the development and evaluation of inclusive policy, service design and delivery, and illuminates the practice of
inclusion in community life. However, the extent to which research informs
inclusive policy varies; for example, Jørgensen (2011) compares the research–
policy nexus in Sweden and Denmark, and concludes that Swedish social sci-
ence researchers have shaped agenda-setting and inclusive migration and inte-
gration policy, whereas in Denmark research has been used more selectively to
justify particular policy in this area.

In order to provide robust evidence to drive socially inclusive practice,
research methods themselves must be socially inclusive. For example, research
that excludes certain population groups from participation due, for example, to
language barriers, may produce results that are not transferable to the omitted
populations. As discussed in previous sections, research should be sufficiently
inclusive of the perspectives of service users in order to design and deliver ap-
propriate and effective services. For example, Read and Maslin-Prothéro (2011)
have reported two case studies from the UK which illustrate the realities of con-
ducting nursing-related research with service users and carers (in this case people
with disabilities and older people) in order to inform service design. Based on
their reflexive research practice and drawing on Fox et al. (2007), they pro-
vide practical examples of implementing six evidence-based recommendations
for user and carer involvement in health and social care research: mutual respect
and partnership working; organisational support; time; effective communi-
cation; financial support; and accessible and meaningful information. Illustrating
the nexus between inclusive research methods and inclusive service delivery in
social work, Mitchell et al. (2009) have drawn on their experiences of research
in the UK with children with disabilities to make recommendations on how best
to involve the views and perspectives of this often excluded population group
in social care processes (and how to embed these skills in social work educa-
tion). They suggest using a range of communication tools, spending time with
and learning how to communicate with children with disabilities, and valuing
non-traditional forms of data and types of knowledge. Disciplines such as market
research have also acknowledged the need to consider meaningfully the views of
potentially excluded groups, and have reflected on ways in which this inclusive
research practice might be achieved. For example, Stevenson (2011) has de-
veloped guidelines for incorporating the views of people with mental health issues
into mainstream market research, including provision of a safe and supportive
environment for focus-group participants and ensuring appropriate moderator
training. The success of the consumer movement in mental health in putting
service user or consumer involvement in research on the political agenda in many
countries is reflected in the recently published Handbook on Service User Involv-
ment in Mental Health Research (Wallcraft et al. 2009).

Practising inclusion across the research process

Socially inclusive research involves practising social inclusion at multiple stages
of the research process: generation of the research question, methodology and
design, sampling and recruitment, data collection, and data analysis/interpretation of
findings. Individuals or groups can be excluded at each of these stages. For example, certain groups may be excluded deliberately from sampling, such as the well-documented gender bias against women in medical research (Holdcroft 2007); excluded indirectly because of inequality in access to research participation, for example by a failure to provide culturally competent or linguistically appropriate research materials such as information, consent procedures, data collection tools or techniques; or marginalised in the analysis and interpretation of results and their translation into practice due to selective privileging of professional or academic expertise. To illustrate inclusion at various stages of the research process, the chapters in Part 6 of the book are now considered alongside examples of contemporary inclusive research practice from the international literature and from a range of health and social research disciplines.

In Chapter 17, Foster and Freeman examine the processes of obtaining informed consent in inclusive research. They discuss research carried out amongst older, socio-economically disadvantaged African migrants in the UK, and reflect on how traditional ‘formal’ research consent procedures may increase the likelihood of these groups being excluded from research. The authors suggest that other forms of consent, such as implied consent, can increase inclusion of marginalised and under-represented groups in research.

Chapter 18 by Graham considers the practice of inclusion in epidemiological research question identification and data analysis. Childless women have been shown to experience multiple forms of social exclusion, including exclusion from the population health research agenda, and in Chapter 18 Graham discusses the research methods necessary to ensure inclusive and robust representation of this often overlooked topic in research. Given the increasing prevalence of childlessness among female populations in high-income countries and the significant negative associations between childlessness and social health and wellbeing, Graham’s recommendations to increase the visibility of childlessness in research are timely and pertinent internationally.

**Participatory approaches to research**

Research methods that have at their core an emphasis on inclusive practice across all stages of the research process have proliferated in recent years as the inclusivity of methods involving a research ‘subject’ have been questioned. For example, Dominelli (2005) reflected on the use of grounded theory methodology within a feminist orientation to research the experiences of young mothers in care in the UK, and concluded that these research techniques positioned participants as subjects and curtailed their full inclusion in the research. In comparison, participatory approaches such as community-based participatory research (CBPR) prioritise the collaborative involvement and agency of the traditionally ‘researched’ community (Minkler and Wallerstein 2008). Such research approaches are increasingly common across a range of health and social care disciplines, and span a variety of study designs, having been used in experimental, intervention and evaluation studies, and in studies using
a range of qualitative approaches, including innovative forms of data collection such as photovoice (see Minkler and Wallerstein 2008; Catalani and Minkler 2010). For example, in the medical research field, it has been recommended that CBPR move from the ‘margin to the mainstream’ (Horowitz et al. 2009: 2633, considering the example of research in cardiovascular health).

A systematic review of CBPR studies concluded that intervention studies using this approach were effective in promoting community health (Salimi et al. 2012). Similarly, de las Nueces et al. (2012) carried out a systematic review of CBPR approaches to enhance clinical trials of ethnic minority groups. They found that ‘trials examined a wide range of behavioural and clinical outcomes, such trials had very high success rates in recruiting and retaining minority participants and achieving significant intervention effects’ (de las Nueces et al. 2012: 1363). The multisite ‘translational community trial’ approach has also been proposed as a means of incorporating CBPR principles in the translation of interventions established through randomised controlled trials to a real-community context (Katz et al. 2011).

As discussed earlier in this chapter, inclusive research practice can underpin the development of inclusive services and their delivery. For example, participatory research approaches have been shown to be useful in this context of mental health service delivery in the USA (Alegria et al. 2011) and reconfiguration of mental health day services in the UK (Bryant et al. 2010). CBPR can also be used to effect policy change, for example policy to eliminate or reduce health disparities (Israel et al. 2010). CBPR has been also been employed extensively in social work research and policy development: for example, Balfour (2011) discusses how CBPR can be used to address rural social (and health) disparities via research partnerships between social workers and rural communities.

In Chapter 15, Grieb et al. explore how CBPR approaches can be used to foster social inclusion in the context of HIV prevention and health promotion. Their research was carried out in the USA, where CBPR has gained ‘national prominence’ (McKenna et al. 2011: 387), particularly in relation to addressing health inequities and disparities between population groups (Wallerstein and Duran 2010). The vulnerable population conceptual model (Flaskerud and Winslow 1998) understands vulnerable populations as ‘social groups who have limited human capital, are of low social status, or lack health care access, and consequently . . . have higher risks for morbidity and premature mortality’ (Wang-Letzkus et al. 2012: 257). Wang-Letzkus et al. (2012) used this model to frame their reflections on carrying out culturally competent CBPR with older diabetic Chinese Americans and recommend:

(a) identifying an accessible community and key persons within the community, (b) obtaining interest and support from the identified communities, (c) using the expertise of community advisors, (d) establishing a culturally sensitive caring partnership, and (e) establishing ownership by sharing research findings with the community.

(Wang-Letzkus et al. 2012: 257)
Also from the USA, Panapasa et al. (2012) discussed using CBPR with community-based organisations and faith-based organisations (FBO) in the Pacific Islander American Health study and concluded 'FBOs represent a valuable resource for community-based participatory research (CBPR) data collection and for effective interventions' (Panapasa et al. 2012: 58).

Chapter 15 by Grieb et al. is representative of a very large volume of CBPR studies that work with community-based organisations, and by doing so, succeed in including previously 'hard-to-reach' groups in health research. They present three case studies in which the CBPR approach has been employed with vulnerable communities in the USA – African Americans, youth, and sexual minorities – and discuss how academic-community partnerships can provide opportunities for communities at risk of social exclusion to play an active and empowering role in the research process and in the shaping of HIV-prevention strategies and health promotion agendas.

There is also a large body of emancipatory and participatory research in disability studies. For example, from the USA, Hassouneh et al. (2011) have described a number of practical strategies that can be used to overcome the challenges in conducting fully inclusive and participatory intervention research with people with disabilities, for example in relation to training and funding. Delman (2012) has summarised key recommendations for carrying out successful participatory action research (PAR) with young adults with psychiatric disabilities, including mentoring for the young adults by more experienced researchers. Lorenzo (2008) carried out a PAR project with women with disabilities in South Africa to mobilise for public transport to enable their equitable workforce participation, and Milner and Kelly (2009) used a PAR approach with vocational service users in New Zealand to examine social inclusion and community participation for people with disabilities. Rights-based emancipatory disability research has also been discussed in the context of Australian social work (Stevenson 2010). In Chapter 16, Wilson and Campain reflect on their experiences as lead researchers in an inclusive research process with people with intellectual disability in Australia, and consider the importance of acknowledging and recognising the key role played by social relationships in carrying out inclusive research, a lesson applicable to the international context.

In addition to the examples above, participatory approaches have been used with a wide variety of other potentially excluded population groups globally, and there is a large body of literature reporting and examining the use of such approaches. For example, an international review of CBPR studies with children and adolescents (Jacquez et al. 2012) concluded that there were overwhelming benefits to partnering with youth in research. Prilleltensky (2010) has advocated PAR approaches to increase child wellness and social inclusion; Ataöv and Haider (2006) have used PAR with street children in Turkey to facilitate their meaningful participation in research, inclusion in public space, and empowerment. At the opposite end of the age spectrum, Doyle and Timonen (2010) have recommended the use of CBPR in gerontology. Hayashi et al. (2012) have used CBPR as an effective research approach with a
vulnerable population group of drug users in Thailand, and Ahari et al. (2012) have reported successfully using health-related PAR with highly socio-economically deprived communities in Iran. O’Neill et al. (2005) used PAR with refugee children and families to address educational needs and explore issues of social justice and social integration. Fenge (2010) reflected critically on the use of PAR with older lesbians and gay men in the UK, recommending the approach as empowering and promoting inclusion. However, Fenge also cautioned that researchers should remain aware that ‘voices can be silenced as well as enhanced by participatory methodologies’ (Fenge 2010: 891), one example is the possibility that group members whose views vary from the majority may feel unable to participate.

Participatory research approaches have also been used to facilitate equitable research partnerships between professional or academic researchers and indigenous peoples in colonised countries internationally. For example, from Canada, Koster et al. (2012) have reported on the application of CBPR in partnership with the Nishnawbe Aski Nation and on the benefits to the community when researching 'for' rather that 'on' them. Wescbe et al. (2011) outlined their experience of CBPR on food security led by the Vuntut Gwitchin First Nation and the multiple positive outcomes and applications of the research. From the USA, Mohammed et al. (2012) provide reflections on effective CBPR techniques when conducting research in partnership with an indigenous community in the Pacific Northwest. They describe the process of developing a data-sharing agreement and qualitative data collection guide that met the needs of both academics and tribal members, and describe ‘a process of negotiation that required: (i) balancing of individual, occupational, research, and community interests; (ii) definition of terminology (e.g., ownership of data); and (iii) extensive consideration of how to best protect research participants’ (Mohammed et al. 2012: 116). In Chapter 19, Barter-Godfrey et al. reflect on their experience, as white academics, of carrying out participatory health-related research with members of Australian Aboriginal communities. They describe how inclusive research approaches can provide an environment that fosters community empowerment and reconciliation and has the potential to address the multiple forms of social exclusion and disadvantage experienced by Australia’s indigenous peoples. Insights from this chapter are applicable to the practice of inclusive research in other countries in which indigenous peoples experience the ‘colonial legacy of multiple deprivations’ (Johner and Maslany 2011: 150).

Barter-Godfrey et al. (Chapter 19) describe their training of, and collaboration with, community researchers from the Australian Aboriginal population. The importance of research capacity building in enabling inclusive and participatory research has also been emphasised elsewhere, for example by Kwon et al. (2012), when reflecting on community empowerment training when carrying out research with community based organisations from the Asian American, Native Hawaiian and Pacific Islander communities in the USA. Such research capacity building in indigenous or any other potentially marginalised communities increases the likelihood of genuinely inclusive research to be generated
and practiced by and with such communities. Barter-Godfrey et al. (Chapter 19) also describe how their project collected, analysed and disseminated research data in socially and/or culturally inclusive forms; again, this principle and practice are applicable to research in other contexts and populations. For example, when carrying out a CBPR project with indigenous peoples in Canada, Christensen (2012) used research storytelling as a method by which the research outcomes could be communicated and disseminated in a culturally congruent manner.

**Achieving successful social inclusion**

Looking across the range of different initiatives that have aimed at including service users, their families/carers, and/or the wider community in policy, service design or delivery, what can be said about the success of these in achieving inclusion and their effects on services and the individuals involved? A number of systematic reviews or syntheses of research provide some partial answers. The earliest of these, by Crawford et al. (2002), examined studies of involving patients in the planning and development of healthcare and identified many case studies. Evidence from these showed that involvement can contribute to a range of changes, including increased service accessibility and improvements in the attitudes of organisations and their staff towards consumers. Most interesting here perhaps is the finding in seven of the 31 studies they reviewed of increased self-esteem in those involved; no studies reported decreased self-esteem, although two studies did report dissatisfaction on the part of those involved. Many studies did not look at the effects of involvement on those who participated.

Nilsen et al. (2010) reported a systematic review of methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. They limited their review to randomised control trials and found six studies involving 2123 participants; they assessed these as having moderate or high risk of bias. They concluded there is moderate-quality evidence that involving consumers in the development of patient information material results in material that is more relevant, readable and understandable to patients, without affecting patient anxiety. This ‘consumer-informed’ material can also improve patients’ knowledge. When setting priorities for community health goals, very low-quality evidence was found that telephone discussions and face-to-face group meetings engage consumers better than mailed surveys; different priorities were also found with different methods.

Preston et al. (2010) examined 37 studies in their review of links between rural community participation and health outcomes. They found some evidence of benefit of community participation in terms of health outcomes, although they identified only few studies at higher quality levels of evidence. Tempfer and Nowak (2011) reported a systematic review of consumer participation in organisational development in healthcare. Unfortunately, this review...
did not examine the consumer experience of involvement. They identified 467 studies including five systematic reviews describing various participation projects, using a variety of methods/processes including: workshops, citizens’ panels, focus groups, citizens’ juries and consultation meetings. They found no discernible trend favouring a specific method. Only six studies had outcome assessment: three judged the outcome as successful, two as negative, and one multi-project study reported ‘very successful’ project assessments in 24 per cent of the projects. In 18 studies, the level of consumer participation was described as ‘informed’ in two, ‘advisory’ in 14, and ‘decision-making’ in only two; this indicates that the majority of initiatives are certainly not acting at the highest rungs on Arnstein’s ladder (see Figure 1.1), and the category ‘advisory’ may well extend down into the lower rungs. They identified a number of factors associated with project success: adequate resourcing; partnerships with well-developed consumer organisations; advanced project logistics; small-scale projects; and adequate internal and external communication.

Of particular interest in terms of its global coverage, Gaventa and Barrett (2010) explored the outcomes of citizen engagement through a systematic meta-analysis of 100 researched case studies of citizen engagement in 20 different countries; most of the cases were from low- and middle-income countries. They examined four different types of outcome: construction of citizenship, including both knowledge and sense of agency and empowerment; strengthening practices of participation; strengthening the responsiveness and accountability of states; and, finally, developing inclusive and cohesive societies. They found positive outcomes in relation to each of these different types of outcome, although not uniformly across all cases, the overall ratio of positive to negative outcomes being 3 to 1. Their findings point to the relative importance of associations and social movements compared to institutionalised fora for participatory governance, and to the need for multiple strategies of engagement. Interestingly, no simple linear relationship between level of democratisation and level of positive outcomes was found; instead, the highest incidence of positive outcomes related to social inclusion and cohesion were in the weakest and most fragile democracies, many of which are characterised by recent histories of conflict or violence.

Finally, and this time focusing particularly on low- and middle-income countries, Mubyazi and Hutton (2012) examined a number of reviews, primary publications and the grey literature, examining community participation in health planning, resource allocation and service delivery. Their conclusion sounds a note of caution, identifying that, although community participation is a concept that is widely promoted, few projects/programmes have demonstrated its practicability in different countries. In many countries, they found the level of participation to be very low, with control remaining with elites or politicians, with professionals dominating the decision-making processes.

Reading across these reviews as well as the earlier parts of this section offers the strong conclusion that considerable flexibility in the methods by which people are involved is required (see also Taket and White 2000; Picard 2005; Mayo and Rooke 2006). Earlier sections noted the value of methods such as
action methods, sociodrama, and photovoice, which include non-verbal forms of representation, and as Taket and White (2000) identify, these methods can help to subvert the usual operation of power and privilege, facilitating those often silenced in being heard. Recent and continuing developments in information and communication technology have increased the feasibility of inclusion in a wide number of settings and domains (Zambrano and Seward 2012). Some methods have been specifically developed for allowing participation at a distance, and in a way so that individuals can contribute views unhindered by perceptions of their personal power or prestige. One example of this is the Delphi method, discussed in the section on service design above. Catalani and Minkler (2010), in their systematic review of the use of photovoice in health and public health find that, particularly among highly participatory projects, photovoice appears to contribute to an enhanced understanding of community assets and needs and to empowerment.

One important factor is individuals’ willingness to be involved in policy, planning, service delivery or research. Here a number of studies indicate that it cannot be assumed that all are equally keen to participate, even if offered an appropriately supported chance. Abelson et al. (1995) found significant differences between groups in the community in terms of willingness to be involved, desired roles and representation in the case of devolved decision-making on healthcare and social services in Ontario, Canada. Participants, perhaps especially in light of understanding the complexity of the decision-making involved, tended to defer to traditional decision-makers (elected officials, experts and the provincial government), and favoured a consulting role for interested citizens, for example at town-hall meetings. Allsop and Taket (2003), studying opportunities offered for participation in a primary care service development in the UK, found that service users believed there should be a high level of user or local community participation. However, most people were only prepared to involve themselves in planning in a very limited way. Allsop and Taket (2003) argue that the apparent contradiction between in principle support for user involvement but reluctance to become personally involved is probably explicable in terms of the perceived costs and benefits for the individuals concerned, in the context of other demands and priorities in their lives. Bryant et al. (2008b) report similar findings in their study of Australian drug treatment services. They identified consumers who indicated they did not want to participate, expressing beliefs that it was ‘not their place’ to be involved and that they lacked the required skills. Similarly, McGrath (1989) found that carers of people with an intellectual disability in Wales were keen to participate in planning for their child’s future, and believed there should be carer input into area plans; however, 63 per cent had little interest in personally contributing at area level.

Perhaps the most detailed examination of willingness to participate is provided by Litva et al. (2009), who explored lay perceptions of user involvement in clinical governance in the UK. They reported that different groups of lay people varied both in their desired role and in their preferred type of involvement in different aspects of clinical governance, as summarised in Table 1.3.
Table 1.3 Preferred role and type of involvement for different groups

<table>
<thead>
<tr>
<th>Role Type</th>
<th>Improving and assessing services</th>
<th>Dealing with poor-performance</th>
<th>Education and training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Citizens</td>
<td>Role: Citizen Type: Overseeing</td>
<td>Role: Citizen Type: Overseeing</td>
<td>No desire to be involved</td>
</tr>
<tr>
<td>Patient user group 1</td>
<td>Role: Citizen Type: Partnership</td>
<td>Role: Citizen Type: Partnership</td>
<td>No desire to be involved</td>
</tr>
<tr>
<td>Patient user group 2</td>
<td>Role: Citizen Type: Informing</td>
<td>Role: Citizen Type: Overseeing</td>
<td>No desire to be involved</td>
</tr>
<tr>
<td>Health interest groups</td>
<td>Role: Advocate Type: Overseeing</td>
<td>Role: Advocate Type: Overseeing</td>
<td>Role: Advocate Type: Partnership</td>
</tr>
<tr>
<td>Frequent users</td>
<td>Role: Consumer Type: Informing</td>
<td>Role: Citizen Type: Overseeing</td>
<td>No desire to be involved</td>
</tr>
</tbody>
</table>

Source: Litva et al. (2009).

There also seems to be an increasing focus on the value of recognising human rights as a basis for inclusionary practice. Examples of this have been discussed in earlier sections of this chapter. Most recently there are the World Psychiatric Association's recommendations (Wallcraft et al. 2011), including respecting human rights as the basis of successful partnerships for mental health. This is taken up in a number of the chapters in this book: Chapter 3 by Layton and Wilson on policy design and people with disabilities; Chapter 5 by Pollock and Taket, on inclusive service development, provides a detailed example of such an approach, based on the recognition of the right of each individual to determine the life they want to lead, and the work described in Chapters 6 (Stagnitti et al), 7 (Goldingay and Stagnitti), 9 (Makhoul et al), 17 (Foster and Freeman) and 19 (Barter-Godfrey et al) can also be seen as strongly rights-based.

A number of the studies discussed above have used approaches based in action research, participatory action research, participatory research and CBPR as a basis for involving various 'hard to reach', disadvantaged, excluded or marginalised groups in service design, and such approaches have been considered in the section on inclusion in research. The participatory approach followed in the work described in Chapter 5 by Pollock and Taket, involving both service providers and service users, produced very important changes in the beliefs and attitudes of the service providers and other stakeholders involved.

The importance of language is illustrated by the careful use of the term 'expert by experience' together with 'expert by profession' in Itzin et al's Delphi study (2010b). The choice of words was deliberate in trying to subvert the traditional power relationships between those who experience violence and abuse and those who provide services. This served to empower the experts by experience that participated in the Delphi process used (personal communication) and gave them confidence to express their views. The specific chapters
illustrating this most explicitly in the current book are: Chapters 5 (Pollock and Taket), 8 (Furlong), 9 (Makhoul et al), 13 (Hanna and Moore), 17 (Foster and Freeman) and 19 (Barter-Godfrey et al).

One challenge a number of authors have referred to is that of achieving ongoing inclusive practice, not limited to one-off initiatives, but instead part of ongoing processes. Chapters 5 and 6 present organisation-wide approaches, with widespread participation from staff as well as service users, as one way of surmounting this challenge. They are in two very contrasting settings: Chapter 5 discusses an non-governmental organisation (NGO) providing community services across the state of Victoria in Australia, whereas Chapter 6 is located in a single primary school in the same state. Gaventa and Barrett’s (2010) findings about the need for multiple strategies point to the advantage of embedding specific initiatives in wider work at different societal levels.

Reading across the findings from these diverse reviews, together with the material in the earlier sections of this chapter, offers some clear messages of guidance to those concerned with practising social inclusion. We close this chapter and the first part of this book with the following list of factors required to achieve authentic inclusive practice:

- authentic, trusting relationships;
- subjecting the political and economic status quo to critical scrutiny and a willingness to challenge it;
- analysis of power relations in the socio-economic–political–cultural context concerned and a willingness to work to change these;
- clear rights-based and anti-discriminatory framework for analysis;
- flexibility and adaptability in terms of methods or processes;
- carefully choosing language to support the above;
- resourcing and support for inclusive practice.
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