PROMOTING PARTNERSHIP
FOR HEALTH

Service user and carer involvement in education for health and social care

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Supporting the Comensus Writing Collective

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Dedication

In the course of our involvement with service user and carer participation in university settings we have lost some valued friends and colleagues along the way. We dedicate this book to those individuals whose untimely deaths mean they will not see this book but who nevertheless contributed greatly to it.

Les Collier
Lillian Hughes
Eileen Johnson
Ian Light
Sandy Richardson

All have in their own way supported us, loved and cared for us, challenged us, been kind to us, made us laugh and inspired us to see this project through. They will be sadly missed and fondly remembered.

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Promoting Partnership for Health

This book is one of six in the 'Promoting Partnership for Health' series published by Wiley in association with the Centre for the Advancement of Interprofessional Education (CAIPE). They address partnership to improve the health and well being of individuals, families and communities from different but complementary perspectives.

Three of the books focus on partnership in practice. Geoff Meads and John Ashworth demonstrate how collaboration has proved critical to effective implementation of health care reforms in many countries around the world. John Glasby and Helen Dickinson assemble authoritative sources from Australia, Europe and North America to understand integrated care from many different angles. Scott Reeves and his colleagues contribute a rigorous and wide-ranging critique of interprofessional teamwork informed by evidence and theory and within a robust framework.

Two of the books focus on interprofessional education as a means to promote collaborative practice. Hugh Barr and colleagues embed findings from a systematic review. Della Freeth and her colleagues marry that evidence with their experience to assist all who are engaged in developing, delivering and evaluating interprofessional education programmes.

Partnership between service providers and users is a recurrent theme throughout the series, a message reinforced persuasively in this book which demonstrates dividends for all concerned when service users and carers are fully engaged in preparing future practitioners for partnership in practice.

Hugh Barr
Series Editor

The books in the series:

Barr, H., Koppel, I., Reeves, S., Hammick, M. & Freeth, D. (2005) Effective interprofessional education: Argument, assumption and evidence.

Freeth, D., Hammick, M., Reeves. S., Koppel, I, & Barr, H. (2005) Effective interprofessional education: Development, delivery and evaluation.

Meads, G, & Ashcroft, J. with Barr, H., Scott, R, & Wild, A. (2005) The case for collaboration in health and social care.

Glasby, J. & Dickinson, H. (2009) International perspectives on health and social care.

Reeves S, Lewin S, Espin S & Zwarenstein M (2010) Interprofessional teamwork for health and social care.

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Foreword: Strike up the Band!

Kathryn Church with David Reville***
**Associate Professor and **Instructor, School of Disability Studies,*
Ryerson University, Toronto, Canada.

> *The thing you've got to learn is not to be afraid of it.*
> (Robbie Robertson, *The Band*)

This book makes a unique contribution to the international body of literature on "user involvement." [1] A significant portion of the text documents what happened in a single university when service users and carers and allied academics worked together to bring their lived experience to the teaching of health and social care. Until now, services and systems have been the major arena for practice, policy, analysis and writing on this topic. At long last, a tipping point into the field of education as a fresh site for activity. Thus, there is much to celebrate.

We celebrate the practice that lies at the heart of this volume. The knowing revealed here, layer by layer, is not your standard academic fare: detached, abstract, speculative. Rather, this knowing is grounded in direct engagement with a tangible project – the initiative called Comensus – and the dilemmas that emerged from that work: day by day, year to year. Here we are offered real people, their actions and interactions in place and time. Situated in social and political context, these particularities resonate widely – across an ocean, in our case. In the sentences assembled, as well as the tensions that run silently between the lines, we recognize the familiar world of our own complex struggles.

We celebrate the array of players whose efforts made both Comensus and this volume possible. As veterans of participatory projects, including research, we know how difficult working across difference can be. In Canada, the lure of grants for community-university partnerships has been strong over the past few years. But rarely do these arrangements extend beyond the terms of the funding. Faced with the challenging "between-ness" of collaborative scholarship – neither this nor that, here nor there, me nor thee – the Comensus players stayed the course. Their grit is our gain as this account disrupts and breaks open the traditional separations between these worlds.

---

[1] In these remarks, we embrace the term "user involvement" while we also use the following: consumer, consumer participation, psychiatric survivors, "mad", and Mad Studies. All of these words are actively "at play" in the mental health and university worlds in Toronto.

We celebrate the writing itself. The literature on participatory action research is thick with suggestions for how participants should work collectively to shape major phases of the process (Mental Health Recovery Study Group, 2009). It is less than forthcoming, however, on how to produce a participatory text; participation often breaks down at the point of writing. Not so with this book. From the moment you crack its pages, you realize that you are reading something different. You anticipate a dominant author and discover a generous collectivity. You search for a status hierarchy and find a level playing field. You expect singularity and are surprised by multiplicity. You steel yourself for turgidity and relax into welcoming prose.

On what basis do we strike up this "band"? For 25 years, David and I have been working on, observing, thinking through and writing about user involvement. We embody a case study that ranges across community, government and university sites from local to international levels. Our first project was a national policy initiative of the Canadian Mental Health Association. From 1984–1988, I staffed the volunteer committee that directed what came to be known as "Building a Framework for Support." Through research, documentation and a couple of daring experiments, this group put consumer participation on the mental health "map" of every province in Canada. David was our first consumer representative, and, later, the first consumer member of the organization's national board of directors.

David*: I was elected to Toronto City Council in 1980 as part of a reform movement that emphasized citizen participation. Open about having a mental health history, I was a member of one of Canada's first mental patients' associations (Reville, 1981). My political base, however, came from work in educational politics and poverty law. When the Mayor set up a task force on discharged psychiatric patients, it was no stretch for me to insist that he appoint people we now describe as "experts by experience". When I introduced Pat Capponi, a recently discharged psychiatric patient and fierce advocate for better housing for her "folks", to Dr. Reva Gerstein, the chair of the task force, I did not know what I had wrought. The alliance that developed between the two women produced significant and long-lasting change. I didn't know that "user participation" was a "thing" until Kathryn recruited me for the policy committee she staffed at CMHA National. By then I had moved on to provincial politics and I took with me a growing reputation as a user who was going to participate come what may. In my second term in the legislature, I was my party's health critic so I was able to put mental health on the agenda much more often than was usual.*

Trying to shift an entire organization – its language, structures and practices – is an enormous challenge on many fronts. I soon discovered a huge gap between my training in psychology and the skills required for national community development. Of necessity, I became a practitioner/learner (for lack of a better term), someone engaged in trial-and-error learning-by-doing that was always, hopefully, just-in-time. David mentored me. I relied on his advice to navigate the turbulence that bubbled up when our attempts to involve new players met with organizational resistance. Through him, I came to understand that our vision for change had to go beyond better service planning. It had to engage the democratic agenda of other social movements. It had to become political.

***David**: As a "leftie" with community organizing experience, I was shocked at how a-political CMHA was. I was shocked, too, at its tolerance of the glacial pace of change. As a city councillor, I'd begged city bureaucrats to open abandoned buildings so that homeless men and women could get in out of the cold; my executive assistant and I cut up sheets of bubble wrap so that they wouldn't have to sleep on bare floors. And here comes the Canadian Mental Health Association wanting to "scan the external environment"?*

CMHA's policy agenda was puzzling, too. The notion that a person with mental health issues needed the support not just of the mental health system but of community agencies, families, friends and peers seemed to me so self-evident that I didn't understand why anybody had taken the trouble to put it into a book. But as I travelled around the country telling the "Framework for Support" story, I began to realize that (a) the story wasn't self-evident and (b) that being a part of national organization provided real opportunities to showcase the "user voice". Were it not for my connection to CMHA, I don't think I would have been invited to the Common Concerns conference. Invitation in hand, I called Kathryn; I needed a paper on user involvement.

"Common Concerns" was held at the University of Sussex, England, in 1988. That international event was likely the first of its kind: a landmark in the "user movement" worldwide. To the assembled company, David delivered our co-authored paper on user involvement in Canada. It was a "work in progress", we argued, pointing to examples of member control over self-help organizations and housing cooperatives, coalitions for supportive legislation and partnerships for progressive policy development. An increasing number of professionals were realizing that they had to learn "not to be afraid of it."

After leaving the mental health association, our collaboration revolved around my doctoral studies. As I embraced sociology, David connected me to the psychiatric survivor leaders whose stories and politics constituted a standpoint for my research. His legislative challenges to the provincial government sparked a series of regional policy consultations that became the lively ground of my formal inquiry. I had a seat in the front row from which to observe the profound "unsettlement" that occurred as people who had been diagnosed and treated by a service system sought to find their way as "knowers" in its governance. The process was emotional and disturbing – a far cry from the cool rationality of "democratic representation." My analysis surfaced the "breaking down/breaking through" of forms and relations, discourses and practices that comes with "passionate participation" (Barnes, 2008). One sharp edge of my personal breakdown was the split in my learning between the university's demands for proper scientific stance and form, and psychiatric survivor demands for authentic presence and activist engagement (Church, 1993; 1995).

In the 1990s, a conservative government took power in Ontario. The years that followed were not kind to participatory initiatives of any sort. David and I were each compelled to reorganize our paid work. He left politics to lead the new Advocacy Commission of Ontario – and to preside over its demise when it was axed by the province. I built a practice as an independent researcher working primarily for psychiatric survivor organizations doing community economic development – an activity favoured by funders of that period. I organized a series of small participatory studies and wrote plain language reports on survivor-run community businesses. These projects demonstrated the flip side of user involvement. Psychiatric survivor organizations set the terms for the work and controlled the funds; I was contractual labour. And while that arrangement clarified our power relations, I grew troubled over identity politics and the uncertain or fleeting impact that community-based research had on policy. Privately, I yearned for greater intellectual freedom.

David*: Involvement with CMHA both nationally and internationally turned me into a kind of poster boy for user participation. Over time, however, my focus shifted to policy and program development designed to create and sustain user-led initiatives. Some of the most successful user-led initiatives were – and remain – community-based businesses. For the employees of such businesses, it is participation by people who are not users that is contentious. The politics of user participation began to change in the early 90s. More and more activists began to identify as survivors rather than users and began to reject offers to merely participate. One user-led organization now feels sufficiently comfortable in its own skin that it is partnering with service providers; it continues to provide social recreation opportunities for its members but also is part of a mental health system program that seeks to keep users out of the justice system. The leadership of another user-led organization has linked up with anti-poverty activists; one of its members has appointed to a panel to advise the government on a review of social assistance.*

By the end of the decade, David and I were both working as consultants within Toronto's community and social services sector. Occasionally, we overlapped into shared projects such as providing advice on the production of the film titled "Working Like Crazy", and sustaining the international discussion generated by its dissemination. We were figuring out how to practice in an altered social and political environment, one in which traditional forums for gathering, exchanging views and creating action had been smudged or erased. We were learning to make do with "the remains of the day": with smaller projects and more fragmentation, with less funding and a more meager array of democratic tools.

In 2002, I joined the School of Disability Studies at Ryerson University. I have since become a tenured faculty member, making the tricky cross-over from mental health to disability writ-large, and expanding my considerations of difference and inclusion in theory and everyday life. Captured by the escalating demands of teaching, research and service, my wisest move was to draw David into the mix. He joined the program in 2004, initially as guest lecturer and co-instructor, and later as a regular, part-time instructor. For seven years, he has been openly and productively "mad" in the academy.

David*: I'm excited to bring user knowledge to 330 students a year; that's how many students enroll in A History of Madness. As gratified as I am about the number, I am even more delighted that the students come from all five university faculties. Students from, say, mechanical engineering, psychology, image arts and information technology management* *may give a group presentation. My other mad course, Mad People's History, is now online, available to anybody with access to a computer. The first module includes a video in which 12 user activists describe how and why they self-label. The final module asks the question: whither mad studies? This book will provide a foundation on which to build a good part of the answer.*

This university adventure looks to be the final iteration of our long grappling with user involvement. It has provoked a number of questions. Are people with mental health histories "experts by experience" only in matters of illness and treatment? Is creating awareness through personal stories the only result we seek from their involvement in the university? David's expertise begins with his mental health history but his fuller contribution is to retrieve the history of a people – a rich and complex body of knowledge that challenges the psychiatric worldview. On the flip side, by weighting "experience" do we devalue the expertise that academics spend years developing? And, from a different angle, are academics experts only with respect to credentialed content in their particular disciplines? Are their "lived experiences" as multi-dimensional human characters never entered into the classroom? There is a personal story – a political autobiography – at the core of my pedagogy. In Disability Studies, I am not alone in insisting upon its relevance as knowledge. And, finally, given the continual reshaping of universities as institutions, can we continue to view them as public institutions? How will user involvement play against the intensification of corporate involvement and funding? Our program has been on the cutting edge of this question for a decade.

***David**: As we start the second decade of a new century, user involvement is making a comeback in Canada. The newly-created Mental Health Commission is trumpeting the amount of user involvement in its deliberations. An all-user consulting team is crisscrossing the country scouting out user participation wherever it may be found. The Commission has funded a huge research study examining the relationship of homelessness and mental health; the studies at the five project sites include varying amounts of user involvement.*

Given the broad relevance of these matters, this book makes a timely appearance. We know that it will be valued – read, quoted, cited, critiqued, even emulated – well beyond the borders of its origins. We congratulate everyone who contributed. Where power relations are deeply entrenched, it takes real courage to venture something new.

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The Comensus Writing Collective: Notes on Authorship

Rather than producing a standard edited text, we have aimed to write a collectively produced multi-authored book.

For the bulk of the book we have practised a process of collective writing, supported by a series of writing team meetings and other individual and peer support, such that authorship of the text is shared. Initial meetings discussed the potential structure and content of the book, agreeing the sort of material we might cover, and the different ways in which individuals might wish to be involved. Different people have facilitated the writing of different chapters, and these have progressed via an iterative process of drafting, peer feedback, and re-drafting. Our notion of authorship involves creative approaches for including the contributions of those individuals who have less experience of writing for publication. Some people have written sections of text, of varying lengths, in more or less a standard approach to writing. Others have preferred to look at drafts of emerging text and bring in their contribution based upon reflecting on these as a starting point. Some people have preferred to sit down individually and talk through their ideas for material to be included, with another person making notes and attempting to draft these out, before passing back to the originator for approval. On other occasions, this sort of thing has been accomplished collectively in group meetings.

Once we were at the stage of having completed drafts of chapters, these were circulated collectively for critical feedback and comments. A smaller group of people was responsible for collating the results of this critical reading process, and incorporating changes into the draft manuscript. A number of us have also contributed quotes which appear at chapter heads, connecting personal reflections on involvement with the thematic content of the specific chapters.

Of necessity, certain chapters have been solely written by named authors, and some sections of other chapters are clearly the contributions of other named individuals. In these instances, authors are explicitly identified at the chapter head, or at the point in the text where their contribution comes in. Though this may seem to go against the grain of our philosophy for a completely collectively written text, the rationale for this emerged out of discussions in the collective.

Our reasoning for a collectivised approach was in some way to shift from standard academic practice of attributing authorship and editorship. We felt that some traditional approaches were less democratic than they might be, and did not always adequately reflect the multiplicity of ways in which contributions to ideas and writings can be made, especially given that our starting point for the book was nested in a participatory action research project. For these reasons, the idea of collective authorship, with all contributors to the collective given equal credit had much appeal within our group. In this sense, our approach is very much in line with the notion of a 'creative commons'.

This simple collective approach, however, runs the risk of devaluing input by individuals who have put a lot of effort into crafting their contribution, and wish to be identified with it. Hence, our decision to properly credit key portions of writing identifiably associated with single authors. These other authors are also credited more widely for other contributions to the collective enterprise elsewhere in the book. We haven't imposed an 'editorial voice' on contributions which are explicitly auto-biographical or describe examples from practice (see Cox et al., 2008). Editorial work was an integral part of collective discussions and the writing process, and not vested in any single individual.

The members of the collective are listed here in alphabetical order:

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The Comensus Writing Collective can be contacted via the Comensus web-pages: http://www.uclan.ac.uk/health/about_health/health_comensus.php

Notes on Language

Our book is about the contribution made to universities by people who have experienced health and social care or who act in the role of informal carer. The language used to describe participants in these endeavours is sometimes controversial and contested. It is our experience not to take these matters for granted.

A focus on choice of terminology is, arguably, more important than idle curiosity or interest in changing fashions. A post-structuralist turn in social sciences suggests that language and discourse are not merely descriptive of objectively verifiable phenomena or social relations. Rather, language and terminology themselves are constitutive, bringing into being that which we recognise as real. The subjective positioning of the viewer or author is privileged in these accounts, and a plurality of ways of making sense of the social world is accepted. The use of different forms of language is often associated with prevailing power relations, with dominant discourses acting to limit or close down alternative or oppositional talk.

In an everyday sense these concerns are exemplified in the wider politics of user involvement in health and social care and, amongst other things, in the debate about use of terminology amongst professional disciplines and lay talk surrounding notions of so-called political correctness. Because ideologies and circumstances can change, individuals who use health and social care services find themselves constructed differently in language as time passes. Examples of this would be the predominance of the term *patient* in circumstances where medical power is in the ascendancy or the language of *consumers* and *clients* at times when individualistic, possibly market driven, ideologies challenged prevailing medical hegemony. Of course, such broad brush trends are complicated by other factors, not least the influence of diverse ideological standpoints or narratives across different health and social care disciplines at different moments in history.

On the face of it, it would seem that the terminology surrounding informal care, that is looking after someone else in an unpaid capacity, typically a relative, is much less contentious than the numerous appellations that have been afforded the role of recipient of formal, professionalised care services. The label carer can be accepted without too much fuss. Though the practice of caring can be associated with aspects of social disadvantage, the role is largely approved of in society. For others, the term 'carer' can be problematic, fore-grounding important socioeconomic and identity issues. The language used to describe people who make use of services, however, can at various junctures be implicitly or explicitly pejorative, demeaning and stigmatising. Different terms applied to this role or identity have appeal for some but not others, and it is very difficult to find a single term that is not flawed in some regard and is acceptable across the board. There are also some variations in use of terminology on an international scale, with slightly different descriptors for key lay participation roles in university settings. This latter point is addressed by the authors of chapter 4, who offer a glossary of some such terms in usage in the US.

Authors of a text which has to cover this territory, hence, are presented with an immediate dilemma over which terminology to favour. Apart from the politics and potential for causing offence to some of the readership we would hope to be interested in this book, there are also practical concerns around reading ease. The latter militate against chopping and changing terms throughout a text, or forever expanding one's descriptors to accommodate all possible nuances of meaning for any given context. This would include repeatedly pausing to explain the pros and cons, or exceptions to, particular terminology at different junctures in the narrative. Ultimately, there is also a need to choose a term that is meaningful to the readership, being instantly recognisable as the entity it is meant to signify. To a large extent this choice involves deciding upon one of the terms which has wide current use. Coining our own neologism would not work in this regard, and certainly couldn't be incorporated in the title of a book that was seeking a broad audience.

Over the years such terms as *patient*, *service user*, *consumer*, or *lay participant* have come in for different criticisms (see Beresford, 2005a; Deber et al., 2005). Similar debates surround the terminology of *disability* and *disabled people* (Swain et al., 2003). The language of *patient* is wrapped up in notions of passive subservience and deference to medical authority and variations on *client* and *consumer*, though in some respects an attempt to indicate greater personal agency, are redolent of a market driven ideology of consumerism that is anathema for some. The current policy vogue for public participation, at least at the level of rhetoric, does not on its own differentiate the particularities of engagement in health and social care from the generalities of the public at large. Terms deployed within the *user movement* that are relevant to our interests here, include *activist* and *survivor*. Despite the notion of activism appearing to often closely fit the behaviour of relevant participants engaged in universities and *community voluntarism*, many people do not recognise the term as fitting in with their view of themselves. The term *survivor* also lacks appeal for many such participants, and, in any event, can have a more recognisably general meaning than its specific use in *service user movement* culture.

In a research context, the notion of *participant* would seem to be superior to *subject*, or other previously relied on depersonalising terminology, including the not uncommon practice in earlier medical journals of describing people's *involvement* under the heading *materials and methods*.

In this book, we have used *service user* and *carer* in the absence of better terms. The term *service user* can be variously criticised, and Beresford (2005a) lists a number of shortcomings. These include disapproval for representing a degree of passivity in encounters with professionals and services, reducing identity to aspects of service usage alone, neglect of the reality that for some people there is a lack of choice in consumption of public services, or for some their use of services is compulsory, and, like all labels, there is a potential for the heterogeneity of personal experience to be obliterated in the homogenising effects of a single term to catch all. Others have objected to the potential for confusion with different notions of *user,* as in the argot of illicit drug use or the view of people as manipulative. There has been some disquiet that the term is perceived as lower status than other professional titles, and this has been noted in a university context by William Park (Chapter 10 this volume). The phraseology of *expert by experience* has been coined to counteract this sort of thing.

The term *service user* has, however, been adopted and employed for radical ends by some in the user movement, and Beresford (2005a) argues that perhaps any negative connotations can be transcended in this context of seeking social change, in much the same way as the notion of disability has been reframed by disability activists. Though we acknowledge the limitations of the term *service user*, it does have currency both in terms of everyday usage within health and social care services, universities and the policy context and it can be seen to have a unifying function across various *disability* and *care* categories to describe:

> *...people who receive, have received or are eligible for health and social care services, particularly on a longer term basis* (Beresford, 2005a: 471).

This definition is flexible enough to bring into its compass people, usually in a context of mental health, who prefer the term *survivor*, and those people who though *eligible* for services, for a variety of reasons choose not to access them.

Our book is about the experiences of service users *and* carers. We do not suggest that these groups are coterminous or share experiences and aims; though there is undoubtedly some common ground, there are also some key differences of interests. Rather, this book is about the involvement of service users *and* carers in universities. Throughout the text, we will refer to *service users and carers* where both have a stake in the topic, but will differentiate as necessary between the two groups. On occasion, the term service user may be used as shorthand for *service users and carers*, where it is clear that both sets of stakeholders are involved, if a degree of succinctness is called for and this can be achieved without compromising clarity.

Introduction

The subject matter of this book is the involvement within universities of people with experience of using health and social care services and informal carers. The main focus is how their knowledge and expertise, born out of personal experiences, can be brought to bear in improving the quality of teaching and learning. Our interest does not stop here, however, and associated involvement ranges over research and other activity within higher education institutions, which can take place independently of teaching but, ideally, connects with and supports the pedagogical enterprise. It is also necessary to acknowledge the socio-political context and issues relating to setting, which firmly locate universities as community based institutions. As such, engagement on this territory raises some key points of interest about the civic role of universities and their relationship with their communities.

Structure of the Book

We have divided the text into two broad sections. The respective sections group chapters thematically under the two headings:

1. The context. This section includes Chapter 1 to 5 and offers discussion of key issues in service user and carer involvement and the role of universities with reference to available theoretical accounts and published literature.
2. Personal experiences: the case of Comensus. This section covers Chapters 6 to 9 and engages with practical applications of theory, addressing service user and carer involvement in universities in practice. Real world examples and personal biographical accounts are drawn on, with key material included from our own experiences within the Comensus initiative at the University of Central Lancashire (UCLan).

The book concludes with a short closing chapter that attempts to synthesise material from the two sections, draw some key overarching conclusions, and outline some aspirations for the future.

The *context* section opens with a general chapter on *Service User and Carer Involvement in Higher Education*. This first chapter reviews developments in the field and places these in a context of general policy background. There is clearly a wealth of engagement between universities and health and social care service users and carers, and the numbers of projects are growing apace. The literature is drawn on to explore the degree to which different reported involvement initiatives embody features of authentic collaboration or partnership, with reference to the analytic framework provided by a notion of a *ladder of involvement*. Reflections on a hierarchy of involvement, from negligible involvement and paternalism to complete involvement and partnership, help to identify key enablers and barriers for effective participation.

Chapter 2 explores *The Social and Political Context* and considers the growth of service user and carer involvement in university settings as possibly part of a wider social movement. Literature and theory developed in the study of social movements can be applied to this specific context affording interesting insights into people's motivations to take part, factors that sustain involvement and relationships and connections within and between groups.

Issues pertinent to the location of universities within their local communities are taken up in Chapter 3: *Beyond the Campus: Universities, Community Engagement and Social Enterprise.* This chapter analyses the different ways in which service user and carer interests are served in various community groups and voluntary sector settings in a context of civic and community engagement. Concepts of social capital, social enterprise and social marketing are critically reviewed and reflected upon for their utility in supporting user and carer involvement. The different ways in which universities can connect with this activity, as supporter or beneficiary, are described as a point of departure for consideration of the notion of a critically engaged institution.

Making the case for service user and carer involvement is greatly assisted in university settings by reference to available research findings. The imperative to properly evaluate novel initiatives is reflected in the content of Chapter 4: *Research and Evaluation of Service Users' and Carers' Involvement in Health Professional Education*. This chapter deals with systematic research methods as well as the more routine audit, evaluation and quality assurance of user or carer involvement. The content of this chapter mainly addresses discussion of relevant methodological approaches, with a more detailed account of outcomes being the focus of Chapter 5.

Chapter 5 addresses the topic of *Outcomes.* In order to determine which outcomes matter, the theoretical basis for health and social care is examined. This is contextualised by the positions of the stakeholders who might have an interest in the commissioning, provision and outcomes of health and social care education. A binary model of professional education is described, with two axes, one of clinical competence and knowledge, the other of attitudes and values. Through an exploration of service user engagement as a complex salutogenic endeavour, the chapter hypothesises that one of the primary outcomes of service user and carer engagement might be the development of moral and ethical maturity in care givers, manifest as emotional intelligence. This provides an essential counter-balance to the clinical and knowledge based weighting of professional education that pertains in the absence of such engagement.

Section Two of the book includes some significant contributions from people either directly involved in the UCLan Comensus initiative, or connected to it in some way. The weight given to this case material is, we feel, justified given the unique approach to systematic involvement across a whole Faculty. It is opportune then, at this juncture, to briefly introduce this particular service user and carer involvement programme. The Comensus initiative has been growing since 2004 in the Faculty of Health at UCLan (Downe *et al.*, 2007). It is an attempt to develop a systematic and comprehensive framework of user and carer involvement that extends into all aspects of the Faculty's work: teaching, research and strategic decision making. The name is not quite an acronym, representing a notion of Community Engagement and Service User Involvement in a University with Support.

Comensus has attempted from the outset to tackle some of the challenges posed by a reading of the literature. We were probably not unique in our own particular starting point, wherein there was a critical mass of academics and community participants connected to the university and interested in user and carer involvement, but previous activity had been piecemeal and uncoordinated. Starting with an affinity for participatory approaches to enquiry and development, and with a commitment to the realization of genuine rather than tokenistic ends, we embarked upon a journey of discovery wrapped up in an action research methodology. The different ways in which participants are supported and support each other has come to be a crucial and valued feature of this work. Along the way we have strengthened established relationships and made new ones with service users, carers, community groups and academics affiliated to our university and other higher education institutions, in this country and abroad. In many respects, it is these relationships and connections which have helped the writing of this book.

Chapter 6 describes and reflects upon the challenges in *Setting up Comensus,* told from the point of view of the person responsible for coordinating the initiative. A portion of the chapter deals with wider theories of organizational culture and how this can be changed by service user and carer involvement. Of course, the chapter also deals with some of the impediments or barriers to change in higher education institutions. The importance of all involved sharing key values and principles associated with authentic involvement is highlighted if these barriers are to be overcome.

As a counterpoint to Chapter 6, the material in Chapter 7 points out the importance of institutional leadership and the capacity to influence systems of bureaucracy and management from the inside. *Climbing the Ladder of Involvement: A Manager's Perspective* describes aspects of these processes and one manager's personal journey in relation to institutional progress towards partnership working in practice.

In Chapter 8 a number of biographical *Stories of Engagement* are presented that span service user, carer, academic staff, involvement development worker and collegiate network coordinator perspectives on service user and carer involvement in university settings. These serve to cast light on the richness and diversity of people's experiences, and the extent to which these endeavours attract compliments and criticism.

In Chapter 9 we return to some of the analyses of social movements first encountered in Chapter 2. These themes are illuminated with reference to the actual ways in which service user and carer participants within Comensus talk about their involvement and how they make sense of it for themselves. These narratives have been collected as part of the action research study that shaped the development of the Comensus initiative.

In some respects, Chapter 10 returns to our opening concerns about the importance of language and terminology. In *Shedding Masks: Transitions in Mental Health and Education, a Personal View*, one individual passionately rejects the constraining aspects of the label *service user*. The humanistic writings of Maslow and Freire are cited to inform a discussion of individuality, creativity and expression. This polemic continues to resonate with a desire to make a positive difference for others, but strives to shake off demeaning features of the appellation *service user* towards reclaiming a positive sense of self and personal identity not defined in terms of health status or service usage.

All of the contributors to this text and, we are sure, many of you, the readers of it, have been involved in some way or other with service user and carer contributions to education, research or other activity in universities or wider communities. In all of this work, and in the production of this book, we have all learnt from each other and engaged in positive, productive and even life-affirming relationships. The first things that become apparent in this context are the enthusiasm and commitment of community participants to make a difference in the university and ultimately endeavour to effect real changes to the actual practice and organization of health and social care services. We hope that the pages of this book reflect the wealth of good practice and learning that is evident in the various examples of university, service user and carer partnerships that are to be found, and in some way make a contribution to the aforementioned goals.

Part I: The Context