

Patient and carer participation in old age psychiatry in England 1: a systemic perspective of the historical and policy context

Professor Susan Mary Benbow, Visiting Professor of Mental Health and Ageing, Staffordshire University and Director of Older Mind Matters Ltd.

* Address for correspondence: Prof SM Benbow, Centre for Ageing and Mental Health, Faculty of Health and Sciences, Staffordshire University, Blackheath Lane, Stafford ST18 0AD, UK.

Email: drsmbenbow@aol.com

Phone: 07789 485435

Office Phone: 01785 353742

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ABSTRACT

Background: Patient and carer participation in old age psychiatry is less developed than in other areas of mental health. What can we learn from the historical context about increasing participation and how can it be conceptualised?

Methods: The historical and policy context of patient and carer participation in the National Health Service is reviewed and related to the development of old age psychiatry in England and the parallel development of the mental health user movement.

Results: Systemic theory is offered as a way of understanding how partnership between healthcare professionals, patients and carers might lead to service evolution by bringing a range of perspectives together in order to co-construct a mutually influenced outcome. It is further suggested that this might not only empower patients and carers but also healthcare staff at a time when they are under increasing pressures.

Conclusions: Old age psychiatry patients and carers struggle to be heard but have much to offer to services in partnership with healthcare professionals as partners and allies in service development.

Keywords:

Geriatric psychiatry; older people's mental health; patient and public involvement; systemic theory; systemic therapy.

The National Health Service (NHS) is the name of the publically funded healthcare system in the United Kingdom. It was created by the National Health Service Act (1946) and has tended to be hierarchical (with a central organising bureaucratic government department), based on what could be described as benign paternalism. It is founded on the principle of healthcare for all, based on need, free at the point of delivery. In this it differs from other healthcare systems around the world.

Historical context

Before the NHS, healthcare in England consisted of a combination of private and public services. Private services included the voluntary hospitals which traditionally provided free care and had developed largely from charitable foundations. Public services were run by local government and had grown out of the Poor Law system. Care was generally fragmented with limited access and wide variations geographically. The National Insurance Act (1911) predated the NHS and introduced sickness benefits funded by contributions from government, employers and employees, but this did not solve the systemic problems. Honigsbaum (1990) stresses the important role of the friendly societies which were formed by working men from the nineteenth century onwards and which provided sickness benefits to members, generally offering a capitation fee to the doctors involved. He argues that the medical profession, in supporting the creation of the NHS, chose state control in preference to control by the societies but this illustrates the inherent difficulty of the conflict between state and health service patient and the core issue of patient participation in health care. (For an account of the evolution of healthcare in Britain see Baggott, 2004).

Honigsbaum (1990) notes that no organised group spoke on behalf of patients in the lead up to the NHS but that the interests of doctors and patients coincided. Aneurin Bevan, then Minister of Health, sent a message to the medical profession in the British Medical Journal (Bevan, 1948) and referred to freeing the 'doctor-patient relationship' from the money factor: participation here referred to the participation of doctors. He also writes that his job is to provide resources and then:

“to leave you alone as professional men and women to use your skill and judgement without hindrance.” (Bevan, 1948)

In effect he asserted the centrality of the relationship between healthcare professional and patient, but this model is unlikely to be acceptable for politicians or public in the twenty-first century. Benign, and hopefully, well-intentioned paternalism (Coulter, 1999) continued to be the approach in the health service for several decades. Ham and Alberti (2002) describe the NHS as established on the basis of an implicit compact between the government (which determined the NHS budget and guaranteed care for all), the medical profession (with responsibility for care standards and delivery) and the public (paying taxes to fund healthcare).

In 1991 the Patients Charter was introduced and later revised in 1995. It set out some fundamental rights for patients. It states that it is helping the NHS to 'listen to and act on people's views and needs'. Much of it remains aspirational today.

The NHS Plan, published in 2000, was promoted as shifting the balance of power in health services towards the patient:

“For the first time patients will have a real say in the NHS. They will have new powers and more influence over the way the NHS works ...”. (NHS Plan, 2000, p. 12)

The Plan aimed to increase the involvement of patients and the public in all aspects of health care. It grew from previous work which had highlighted three partnership areas: with patients and carers in connection with their own care; with patients and carers more generally in health and social care; and with the public as citizens who have a stake in health and social care, and followed the publication of a National Carers’ Strategy.

Since the NHS Plan, the rhetoric of health and social care policy documents produced by the Westminster government has continued to stress greater choice, greater influence in services at all levels, more individualised care for patients and recognition of the important role of carers. The language used is interesting in that it concentrates on giving people more choice, putting people ‘in control’, services being ‘patient-led’, but, at the same time, emphasises partnership and collaboration with patients, carers and members of the public. Terminology is, however, inconsistent. The House of Commons Health Committee (2007) used the term ‘patient and public involvement’ (but then described the term as a ‘nebulous and ill-defined concept’).

For clarity, this paper uses the following terms:

- Patient for people who are or have been clients or consumers or users or survivors of health or social care (there is debate about the preferred term eg Simmons *et al.*, 2010);
- carer for the family members/ family carers/ friends or neighbours supporting patients; and

- participation to describe the involvement of patients and carers in services in various ways. This is taken from Arnstein's ladder of citizen participation (described in Hostick, 1998: see Figure 1) and is a form of what can be described as public participation: public participation involves organisational engagement, and contrasts with individual participation (an individual's everyday choices) and social participation (collective activities).
- The term user movement is retained in connection with mental health (see below).
- The term client is retained for people using systemic therapy services.

Despite the good intentions of policy documents, structures for patient and public participation have been unstable. Community Health Councils (CHCs), established in 1974 in England and Wales, introduced a framework for patient and public involvement. Their abolition was heralded by the NHS Plan and in 2002 Patient Advice and Liaison Services (PALS) were established in England in all Primary Care Trusts and NHS Trusts. They were followed in 2003 by the establishment of the Commission for Patient and Public Involvement in Health (CPPIH), the Independent Complaints Advocacy Service (ICAS) and Patient and Public Involvement (PPI) Forums: the latter were then replaced by Local Involvement Networks (LINKs) in 2007 alongside the abolition of the CPPIH (for a summary of milestones in PPI see Andersson *et al.*, nd). Talk of partnership continues: in 2009 The Department of Health published the NHS Constitution which stresses partnership, and sets out rights and responsibilities for both patients and staff.

Ham and Alberti (2002) argued that the implicit compact between government, healthcare professions and public has been undermined and broken down in response to changes over recent years and that a new one needed to be agreed. They saw trust and good communication between all parties as fundamental to this process. The participation of patients and carers in health and social care therefore carries far-reaching implications.

The mental health user movement

Wallcraft and Bryant (2003) define the user movement as follows:

“The term ‘service user/survivor movement’ refers to the work of individuals who advocate for their personal and collective rights within the context of discrimination faced as a result of having experienced mental health difficulties and/ or being diagnosed as having a mental illness.” (p 3)

and date its origins to as far back as the early 1600s.

Campbell (1996) dates the upsurge in the user movement to the mid 1980s and cites the pace of change in mental health services as creating uncertainties and hence opportunities for new ideas, alongside the growth in self-help, the anti-psychiatry movement and the influence of user movements in other countries. Crossley (1999) cites similar factors in its development, dating the movement’s birth to the early 1970s, and registering the strong involvement of non-users in the initiation of the movement, perhaps related to their position of power. Campbell (1996) notes the need to increase participation amongst groups which experience multiple exclusions, referring specifically to black and minority ethnic groups (but older adults may be

equally or even more invisible and excluded). Wallcraft *et al.* (2003) surveyed the service user movement in the early 21st century and found that it did not represent or include all mental health service users. In questions relating to equality, their questionnaire omitted issues relating to older age, asking only about minority ethnic groups, women's issues, and lesbian, gay and bisexual issues. Although one responding organisation referred to older people as a community of interest, overall older adults were conspicuous by their absence. Many of the big issues for the user movement in the past were probably not those which older adult groups would have regarded as pivotal eg access to employment and detention under mental health legislation.

Older people's mental health

Old age psychiatry (also called geriatric psychiatry, psychogeriatrics, psychiatry of the elderly, and older people's mental health) is a relatively young speciality which concerns mental health services across the range of mental health problems in later life. It has developed over the past 40 years, with specialty status being achieved in the United Kingdom in 1989 (Pitt *et al.*, 2006). Thus the specialty has been developing over the period when the user movement has been developing.

Patients of old age psychiatry services may be disadvantaged by several factors including: co-morbid physical illness, sensory impairments, multiple medication use, frailty associated with advanced age, social circumstances, co-morbid cognitive impairment along with other mental illness, limited finances, and the assumptions people make about advanced age and cognitive impairment. These factors are

relevant to the relative absence of older patients within the user movement. Carers are more visible and carer support has been described as 'a fundamental component of all aspects of service provision' (Benbow and Jolley, 2006). Although the role of the family in the care of children is clear and accepted, for older adults the case has had to be made (perhaps another example of ageist assumptions) (Benbow and Marriott, 1997).

With regard to older people's mental health (OPMH) policy the National Service Framework (NSF) for Older People emphasised person-centred care (Standard 2) and the issue of choice, and the National Service Framework Mental Health included a Standard on carer support. Unfortunately old age psychiatry fell between the two NSFs: when the NSF for Mental Health was published it did not apply to older adults and the NSF for Older People highlighted other priorities. Everybody's Business (2005) was later produced as a document focussed on older people's mental health and described involvement of patients and carers in services as 'central to quality improvement', arguing that it should be embedded in the way staff and organisations operate. Everybody's Business appears to have had little influence, probably for several reasons: it brought no money into services, was a web-based document and was followed by a period of financial stringency and considerable upheaval in services. More recently the National Dementia Strategy (2009) identifies 'engaging with public and patients' as one of the World Class Commissioning competencies which fits with many of the Strategy's objectives, describing people with dementia and their carers as being fully engaged in the design and delivery of services.

New Horizons: a shared vision for mental health, published in 2009, makes the point that:

“ Older people (should be) equally involved in the planning of their own individual care, service planning, foundation trust membership etc ...” (p. 85)

and includes older people and their care firmly within the sphere of mental health.

Despite these encouraging documents patient and carer participation appears to have had, at best, a limited impact on old age psychiatry services in the UK. There are probably several reasons for this. One major reason is the persisting stigma attached to being older, coupled with the stigma of psychiatry and of possibly having cognitive impairment. These combine to make it more difficult for older people with mental health problems to get their voices heard. In addition the recent drive towards age equality in services in the UK has sometimes been misunderstood as meaning that old age psychiatry services are themselves inherently ageist, since they are targeted at older people. (An alternative view is that to deny the specialist needs of older adults is itself age discrimination.)

Why is patient and carer participation a policy imperative?

Thus it is clear that patient and carer participation is regarded as a policy imperative in the NHS, and a range of policy documents state that this participation carries a number of benefits, including the following:

Shaping services

Improving health outcomes

Ensuring quality

Coulter (nd) distinguishes between the potential benefits of patient involvement and public involvement (Table 1). A number of documents also reinforce an assumption that, as stakeholders in services, patients and carers have a right to influence how those services are provided. Putting People First, a government document on adult social care published in 2007, states that:

“real change will only be achieved through the participation of users and carers at every stage.” (p. 1)

Given the clarity of policy on the issue, it is interesting that patient and carer participation has not already become embedded within English health and social care systems. Soffe *et al.* (2004) surveyed the attitudes of clinical psychologists (in adult mental health services) to patient involvement and noted a discrepancy between policy and practice, suggesting that ways of understanding this include the assumption that ‘staff know best’ and also that:

“staffs’ (sic) sense of disempowerment within the system (may render) them unable to hear users’ voices until their own voices (are) heard ...”. (Soffe *et al.*, 2004, p. 591).

They also note that patient involvement may be threatening to staff, may impact on professional autonomy, and could potentially reduce the future role for staff groups in mental health services.

The House of Commons Health Committee (2007) cautioned that:

“Structures and procedures ... will have little effect if the health service is not prepared to listen and make changes as a result of what they learn.” (House of Commons Health Committee, 2007, p. 5)

If learning from, and working with, patients and carers are seen solely as policy drivers, it is unlikely that patient and carer participation will become embedded in future health and social care practice. Rose *et al.* (2002) articulate this bluntly:

“There is a danger that government demands for agencies to demonstrate user involvement may mean that user activities become a formal procedure to be ticked off, rather than an embedded and powerful organisational practice.”

(Rose *et al.*, 2002, p. 16-17)

Cynics might wonder whether government emphasis on patient and carer involvement is just a means of shifting blame and the onus for change away from health structures and onto patients and carers or merely a populist ploy. In reality patient and carer participation carries costs and, at a time of budgetary constraints, has dropped down the agenda of healthcare commissioning and provider organisations.

What are the benefits and drawbacks of patient and carer participation in healthcare?

It may appear that patient, carer and public participation in health care is largely an item of faith which asserts that it must bring benefits and that people have a right to be involved. There is, however, evidence in the literature of both benefits and drawbacks to patient and carer participation.

Table 2 sets out possible benefits of patient and carer participation and Table 3 possible drawbacks/ constraints. Some of the drawbacks of patient and carer participation can be cited as arguments against participation initiatives. Both Tables

use headings taken from Hickey and Kipping's work (1998) in order to separate both benefits and drawbacks into those relating to each of four areas: patient/ carer issues, professional culture, organisational culture and the wider society. This separation opens up the possibility that what may constitute a benefit in one area may at the same time constitute a drawback in another, eg changes to organisational culture may be regarded negatively by professionals but positively by patients and carers (or vice versa). This highlights the complexity of research into participation. The contents of both Tables 2 and 3 represent a distillation of the literature with inclusion of the author's interpretation of benefits which can reasonably be extrapolated from it.

Hickey and Kipping (1998) argue that it is important to be realistic and to identify constraints in order to consider possible ways of overcoming them or, if they cannot be overcome, to avoid developing unrealistic expectations. However, the current literature focuses more on benefits and on processes of participation rather than outcomes. The lack of literature on constraints and drawbacks may reflect publication bias and adds further weight to the need to develop research on patient and carer participation in old age psychiatry.

A systemic perspective

Dallos and Draper (2010) have chronicled the evolution of systemic therapy from its origins in cybernetics and systems theory in the 1950s along a rich and complex path into the 21st century as an integrated body of theory, applicable to institutions and organisations as well as therapy. They describe family therapy as

“a collaborative process, involving a co-construction of new ways of seeing problems ... (which) requires a sociological awareness of issues of power ... Added to this the therapist is expected to be aware of ... potentially oppressive assumptions and practices inherent in their privileged position of power and status...”. (Dallos and Draper, 2010, p. 97)

Some of its ideas can usefully be applied to healthcare and the participation of patients and carers.

Systemic theory argues that bringing together and exchanging a range of differing ideas and perspectives leads to creativity, dialogue and the evolution of ideas (Inger and Inger, 1990). The idea of double description originated in the work of Bateson and is described by Jones (1993) as follows:

“obtaining more than one view of an event would enable us to achieve the cognitive or emotional equivalent of binocular vision, thus gaining, in a metaphorical sense, perspective on our observations and experiences.”

(Jones, 1993, p. 31)

However, the relationship between those involved is critical to developing the outcome. When Cecchin (1992) wrote that:

“what we discovered depended on the ‘discoverer’ ...”. (Cecchin, 1992, p. 89)

he was writing about therapy, but could have been writing about encounters in both health and social care.

In systemic therapy it has been argued that power stems from the use of expert language and its imposition on the client’s experience (Anderson and Goolishian, 1990). This criticism may be equally applicable to encounters in health and social

care. In systemic therapy over the past twenty years or so there has been a move away from power and control (Hoffman, 1993) towards an emphasis on collaboration (Anderson, 2007a) and dialogue (Anderson, 2007b). Alongside this is debate about 'not-knowing' and 'client-as-expert' (Anderson, 2005). The concepts of 'not-knowing' and 'client-as-expert' involve respect and dignity for the client or patient and their family, a recognition that they hold expertise regarding their own/ their family member's illness and/ or circumstances, and a humble acceptance of the fact that the therapist or health professional doesn't necessarily know best, but must work with the family to help them determine which path to take. These concepts are not threats to the knowledge, expertise and skill of the therapist (or health/ social care professional): instead they make the expertise of the professional available in partnership with the knowledge and experience of patient and carer. They provide foundations for a more balanced collaborative relationship between therapist (or health/ social care professional) and the patients and carers they encounter. The reflecting team (Andersen, 1992) is a way of sharing the ideas of therapists with families. Before it was introduced, families often met with therapists and were 'observed' by a team from behind a one-way screen. When the team came out from behind the screen and talked together about their ideas with the family listening, they became a reflecting team. This, then, was a move away from paternalism and secrecy towards openness and collaboration. It also involved a change in the power balance between families and the professionals working with them, a shift which has continued. Anderson (2007a) has described collaborative therapy as a philosophical stance or way of being:

"The therapist wants to learn and understand the client from the client's perspective and preferences. The therapist wants to learn the client's lived

experience and the meanings and understandings associated with it.”

(Anderson, 2007a, p. 47)

This need for understanding is important in healthcare and underlies person centred care and the burgeoning interest in the importance of relationship between healthcare staff and their patients (Bridges *et al.*, 2010). These systemic concepts encapsulate the idea of circular relationships, of bidirectional influences and the way in which the process between therapist and family (or in healthcare between staff, patients and families) is mutually influenced and mutually influencing.

Taking this perspective enables patients and carers to exert more control, to subvert the expected power structure and start to influence the agenda and strategy of the organisation they are working with, to the benefit of all concerned. It involves what Rober (2005) describes as receptivity and reflection on behalf of all those concerned. He goes on to write that:

“understanding becomes an active, creative process in which the meanings of the client make contact with the meanings of the therapist. In this process, new meanings emerge that are different from the original meanings of the client.” (Rober, 2005, p. 481)

Systemic theory suggests that collaboration with patients, carers and the public might be expected to lead to change and evolution of services. This is not regarded as the pinnacle of participation in Arnstein's ladder, but to privilege citizen control (see Figure 1) is to replace one hierarchical system with another. Although the patient inevitably participates (in a narrow sense) in any encounter with a health or social care professional, a systemic perspective indicates that what is important is

the collaboration, the mutual exchange of views and the construction of an outcome which has been influenced by all participants in the interchange. At a time when healthcare professionals in the NHS feel increasingly disempowered, they might themselves gain from a closer partnership with their patients and patients' families.

Conclusions

Although the participation of patients and carers is regarded as NHS policy and the user movement has had considerable impact on mental health services, both have had less impact in old age psychiatry for a number of reasons including ageism and the triple stigma of age, mental ill-health and possible cognitive impairment. From a systemic perspective increasing participation of patients and carers in old age psychiatry should influence service development and facilitate the empowerment of older adults and their families. It is important that professionals support patient and carer participation, and we argue that the resulting partnership can also empower and support healthcare staff. At a time of considerable pressure on the NHS in the UK, patients and their families are our best allies.

Conflict of interest declaration

None.

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References

Note: A list of Department of Health publications included in this paper can be obtained from the author or from www.dh.gov.uk

Andersen, T. (1992). Reflections on reflecting with families. In S. McNamee and K.J. Gergen, (Eds.) *Therapy as social construction* (pp. 54-68) London: Sage Publications.

Anderson, H. (2005). Myths about “not-knowing”. *Family Process*, 44, 497-504.

Anderson, H. (2007a). The heart and spirit of collaborative therapy: the philosophical stance- “a way of being” in relationship and conversation. In H. Anderson and D. Gehart, (Eds.) *Collaborative therapy Relationships and conversations that make a difference* (pp. 43-59) London: Routledge.

Anderson, H. (2007b). Dialogue: people creating meaning with each other and finding ways to go on. In H. Anderson and D. Gehart, (Eds.) *Collaborative therapy Relationships and conversations that make a difference* (pp. 33-41) London: Routledge.

Anderson, H. and Goolishian, H. (1990). Beyond cybernetics: comments on Atkinson and Heath's further thoughts on second order family therapy. *Family Process*, 29, 157-163.

Andersson, E., Tritter, J. and Wilson, R. (Eds.) (nd). *Healthy democracy the future of involvement in health and social care*. London: Involve and NHS National Centre for Involvement. Available at: <http://www.involve.org.uk/wp-content/uploads/2011/03/Healthy-Democracy.pdf> [Accessed 21 April 2011].

Baggott, R. (2004). *Health and health care in Britain*. 3rd ed. Basingstoke: Palgrave MacMillan.

Benbow, S.M. and Jolley, D. (2006). Organisation of services in geriatric psychiatry. In J. Pathy, A. Sinclair and J. Morley, (Eds.) *Principles and Practice of Geriatric Medicine* (pp. 1163-1171) 4th ed. Chichester: Wiley.

Benbow, S.M. and Marriott, A. (1997). Family therapy with elderly people. *Advances in Psychiatric Treatment*, 3, 138-145.

Benbow, S.M., Taylor, L. and Morgan, K. (2008). Multiple perspectives: Involving users and carers in educating health and social care professionals. *Quality in Ageing*, 9 (2), 12-17.

Bevan, A. (1948). A message to the medical profession from the Minister of Health. *British Medical Journal*, 2 (4565), 1.

Bridges, J., Flatley, M. and Meyer, J. (2010). Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies*, 47 (1), 89-107.

Campbell, P. (1996). The history of the user movement in the United Kingdom. In T. Heller *et al.*, (Eds.) *Mental Health Matters* (pp. 218-225) Basingstoke: Palgrave MacMillan.

Cecchin, G. (1992). Constructing therapeutic possibilities. In S. McNamee and K.J. Gergen, (Eds.) *Therapy as social construction* (pp. 86-95) London: Sage Publications.

Coulter, A. (1999). Paternalism or partnership? *British Medical Journal*, 319, 719-720.

Coulter, A. (nd). Patient engagement: why is it important? In E. Andersson, J. Tritter and R. Wilson, (Eds.) *Healthy democracy the future of involvement in health and social care* (pp. 27-35) London: Involve and NHS National Centre for Involvement.

Available at: <http://www.involve.org.uk/wp-content/uploads/2011/03/Healthy-Democracy.pdf> [Accessed 21 April 2011].

Crawford, M.J. et al. (2002). Systematic review of involving patients in the planning and development of health care. *British Medical Journal*, 325 (7375), 1263.

Crawford, M.J. et al. (2003). User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. *Acta Psychiatrica Scandinavica*, 107, 410-414.

Crossley, N. (1999). Fish, field, habitus and madness: the first wave mental health users movement in Great Britain. *British Journal of Sociology*, 50 (4), 647-670.

Dallos, R. and Draper, R. (2010). *An introduction to family therapy. Systemic theory and practice*. 3rd Edition. Maidenhead: Open University Press.

Doel, M. et al. (2007). Participation: finding out what difference it makes.

Stakeholder Participation Guide 20. London: SCIE. Available at:

<http://www.scie.org.uk/publications/guides/guide20/files/guide20.pdf> [Accessed 2 August 2010].

Haeney, O., Moholkar, R., Taylor, N. and Harrison, T. (2007). Service user involvement in psychiatric training: a practical perspective. *Psychiatric Bulletin*, 31, 312-314.

Ham, C. and Alberti, K.G.M.M. (2002). The medical profession, the public, and the government. *British Medical Journal*, 324, 838-42.

Hickey, G. and Kipping, C. (1998). Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing*, 7, 83-88.

Hoffman, L. (1993). The case against power and control. In *Exchanging voices. A collaborative approach to family therapy* (pp. 5-55) London: Karnac Books.

Honigsbaum, F. (1990). The evolution of the NHS. *British Medical Journal*, 301, 694-699.

Hostick, T. (1998). Developing user involvement in mental health services. *Journal of Psychiatric and Mental Health Nursing*, 5, 439-444.

House of Commons Health Committee (2007). *Patient and public involvement in the NHS: Third report of sessions 2006-7 Vol 1*. London: HMSO. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076380 [Accessed 21 April 2011].

Ikkos, G. (2003). Engaging patients as teachers of clinical interview skills. *Psychiatric Bulletin*, 27, 312-315.

Inger, I.B. and Inger, J. (1990). *Co-constructing therapeutic conversations. A consultation of restraint*. Hampshire: DC Publishing.

Jones, E. (1993). Working in teams. In *Family systems therapy. Developments in the Milan-systemic therapies* (pp. 30-54) Chichester: Wiley.

Lammers, J. and Happell, B. (2003). Consumer participation in mental health services: looking from a consumer perspective. *Journal of Psychiatric and Mental Health Nursing*, 10, 385-392.

Pilgrim, D. and Waldron, L. (1998). User involvement in mental health service development: How far can it go? *Journal of Mental Health*, 7, 95-104.

Pitt, B., Arie, T., Benbow, S.M. and Garner, J. (2006). The history of old age psychiatry in the UK. *IPA Bulletin*, 23 (2), 8-10.

Repper, J. and Breeze, J. (2007). User and carer involvement in the training and education of health professionals: a review of the literature. *International Journal of Nursing Studies*, 44, 511-519.

- Rober, P.** (2005). The therapist's self in dialogical family therapy: some ideas about not-knowing and the therapist's inner conversation. *Family Process*, 44, 477-495.
- Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P. and Wykes, T.** (2002). *User and carer involvement in change management in a mental health context: Review of the literature*. Report to the National Coordinating Centre for NHS Delivery and Organisation RandD (NCCSDO). London: NCCSDO (revised 2003). Available at: <http://www.sdo.nihr.ac.uk/files/project/17-final-report.pdf> [Accessed 21 April 2011].
- Rutter, D. et al.** (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science and Medicine*, 58, 1973-1984.
- Simmons, P., Hawley, C.J., Gale, T.M. and Sivakumaran, T.** (2010). Service user, patient, client, user or survivor: describing recipients of mental health services. *The Psychiatrist*, 34, 20-23.
- Simpson, E.L. and House, A.O.** (2003). User and carer involvement in mental health services: from rhetoric to science. *British Journal of Psychiatry*, 183, 89-91.
- Soffe, J., Read, J. and Frude, N.** (2004). A survey of clinical psychologists' views regarding service user involvement in mental health services. *Journal of Mental Health*, 13 (6), 583-592.
- Spencer, J. et al.** (2000). Patient-oriented learning: a review of the role of the patient in the education of medical students. *Medical Education*, 34, 851-857.
- Stringer, B., Van Meijel, B., De Vree, W. and Van Der Bijl, J.** (2008). User involvement in mental health care: the role of nurses. A literature review. *Journal of Psychiatric and Mental Health Nursing*, 15, 678-683.
- Walker, E. and Dewar, B.J.** (2001). How do we facilitate carers' involvement in decision making? *Journal of Advanced Nursing*, 34, 329-337.

Wallcraft, J. and Bryant, M. (2003). The mental health service user movement in England. Policy Paper. London: Sainsbury Centre for Mental Health.

Wallcraft, J., Read, J. and Sweeney, A. (2003). *On our own terms. Users and survivors of mental health services working together for support and change.* London: Sainsbury Centre for Mental Health.

Wright, P., Turner, C., Clay, D. and Mills, H. (2006). The participation of children and young people in developing social care. SCIE Guide 11. Available at: <http://www.scie.org.uk/publications/guides/guide11/index.asp> [Accessed 2 August 2010].

Wykurz, G. and Kelly, D. (2002). Developing the role of patients as teachers: literature review. *British Medical Journal*, 325, 818-821.

Prepublication version

Figure 1: Arnstein's ladder of citizen participation modified from Hostick (1998)

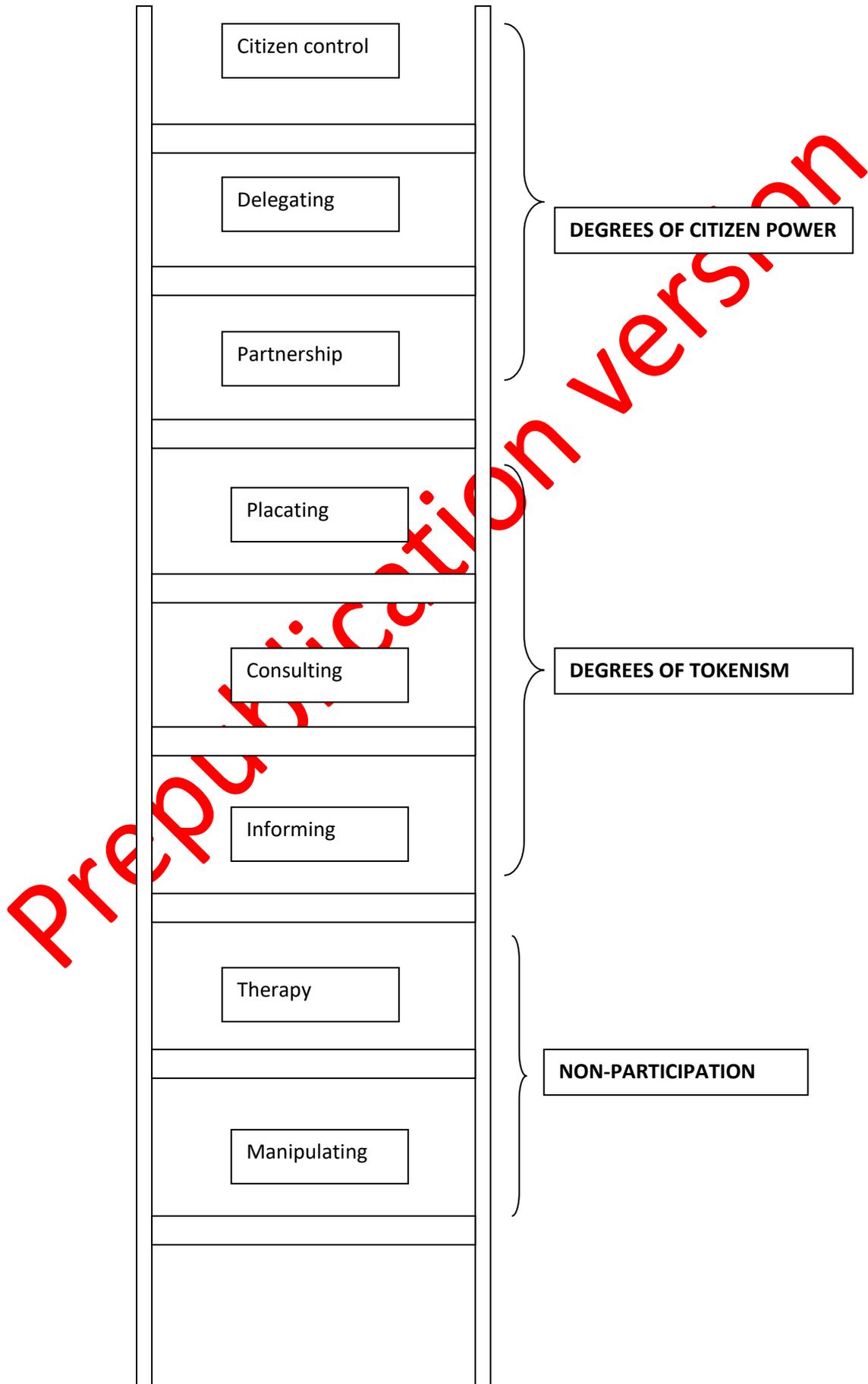


Table 1: Potential benefits of patient involvement and public involvement, modified from Coulter (nd)

Patient involvement	Public involvement
To ensure appropriate treatment, management and care	To improve service design and delivery
To improve health outcomes	To determine commissioning priorities
To reduce risk factors, prevent ill-health and promote health	To manage demand
To improve safety	To meet expectations
To reduce complaints and litigation	To strengthen accountability

Table 2: Benefits of patient and carer participation in aspects of old age psychiatry divided into the categories identified in Hickey and Kipping (1998).

Patient/ carer issues	Professional culture	Organisational culture	Wider society
<ul style="list-style-type: none"> • Promotion of further patient/ carer involvement initiatives (Doel <i>et al.</i>, 2007). • It uses their condition/ knowledge/ experience positively (Wykurz and Kelly, 2002). • Empowers patients/ carers (Wykurz and Kelly, 2002) • Presents an opportunity to help future patients/ carers (Wykurz and Kelly, 2002). • Increases their knowledge/ gives new insights (Wykurz and Kelly, 2002). • Improves their understanding of professionals/ organisations (Wykurz and Kelly, 2002). • May lead to services more attuned to the needs of patients/ carers (Stringer <i>et al.</i>, 2008). • May improve treatment compliance/ health outcomes/ quality of life (Stringer <i>et al.</i>, 2008; Crawford <i>et al.</i>, 2002; 	<ul style="list-style-type: none"> • Increased experience of patient/ carer involvement initiatives. • Increases their knowledge/ gives new insights (Wykurz and Kelly, 2002). • Improves their understanding of patients/ carers perspectives and experiences (Ikko, 2003; Repper and Breeze, 2007; Wykurz and Kelly, 2002). • May improve treatment compliance/ health outcomes/ quality of life (Stringer <i>et al.</i>, 2008; Crawford <i>et al.</i>, 2002) • May lead to a safer environment for 	<ul style="list-style-type: none"> • Embedding of patient/ carer involvement initiatives in organisational culture. • Improves organisational understanding of patients/ carers perspectives and experiences. • Changes to service priorities may result (Doel <i>et al.</i>, 2007). • Changes to management systems may result (Doel <i>et al.</i>, 2007). • Services may be more accessible (Crawford <i>et al.</i>, 2002). • Service may be more responsive to the needs of older adult patients and carers (cf children: Wright <i>et al.</i>, 2006). • Services may be more acceptable (Crawford <i>et al.</i>, 2002). • May benefit the 	<ul style="list-style-type: none"> • Beneficial effect on attitudes towards mental illness and those with mental ill-health. • Improved service provision, planning and improvement. • Improved education/ training of professionals in health and social care. • Participation embodies a sound democratic principle (Rutter <i>et al.</i>, 2004). • Challenges presumptions about the needs of older adults patients and carers (cf children: Wright <i>et al.</i>, 2006).

<p>Walker and Dewar, 2001).</p> <ul style="list-style-type: none"> • May increase patient/ carer satisfaction (Stringer <i>et al.</i>, 2008). • May lead to a safer environment for patients/ carers (Stringer <i>et al.</i>, 2008). • May improve self confidence and self-esteem (Stringer <i>et al.</i>, 2008). • Enjoyment (cf children: Wright <i>et al.</i>, 2006). • Opportunity to develop social networks (cf children: Wright <i>et al.</i>, 2006). • Spencer <i>et al.</i> (2000) suggest that patients might feel more 'enabled' after involvement in teaching ie better able to cope with their condition. 	<p>staff (Stringer <i>et al.</i>, 2008).</p> <ul style="list-style-type: none"> • May improve job satisfaction. 	<p>organisation by improving health outcomes (Stringer <i>et al.</i>, 2008; Crawford <i>et al.</i>, 2002).</p> <ul style="list-style-type: none"> • Patients/ carers may be more satisfied with services (Doel <i>et al.</i>, 2007). • May lead to safer environment which benefits the organisation by reducing risks. • May impact on staff turnover, sickness rates etc. • Changes to organisational attitudes/ culture (Crawford <i>et al.</i>, 2002). 	
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Prepublication version

Table 3: Constraints on/ drawbacks of patient and carer participation in old age psychiatry divided into the categories identified in Hickey and Kipping (1998)

Patient/ carer issues	Professional culture	Organisational culture	Wider society
<ul style="list-style-type: none"> • Impact of patient mental health/ carer stress on decision-making ability. • Impact of participation on patient/ carer mental health (Simpson and House, 2003). • Patients/ carers may decide not to take part in decision-making. • Patients/ carers regarded as not representative (Crawford <i>et al.</i>, 2003; Simpson and House, 2003; Repper and Breeze, 2007; Benbow <i>et al.</i>, 2008). • Remuneration – effect on benefits (Haeney <i>et al.</i>, 2007). • Dissatisfaction with what is offered (Rutter <i>et al.</i>, 2004). • Patients/ carers desire for independence (Rutter <i>et al.</i>, 2004). 	<ul style="list-style-type: none"> • Lack of recognition of the ability of patients to contribute. • Use of language which excludes patients/ carers (Lammers and Happell, 2003). • Patient decision-making seen to undermine/ threaten staff/ 'professional autonomy' (Soffe <i>et al.</i>, 2004). • Increased involvement of patients may decrease the role of staff (Soffe <i>et al.</i>, 2004). • Disempowerment of front-line staff (Soffe <i>et al.</i>, 2004). 	<ul style="list-style-type: none"> • 'Tokenism' - lack of limited commitment to participation (Crawford <i>et al.</i>, 2003; Rutter <i>et al.</i>, 2004; Simpson and House, 2003). • Lack of resources to support participation (Crawford <i>et al.</i>, 2003; Pilgrim and Waldron, 1998). • Lines of accountability preclude active decision-making. • Uncertainty about how to achieve participation (Rutter <i>et al.</i>, 2004). • Conflicting management priorities (Rutter <i>et al.</i>, 2004). • A strategy to legitimise unpalatable change eg rationing (Rutter <i>et al.</i>, 2004). 	<ul style="list-style-type: none"> • Attitudes towards mental illness and those with mental ill-health. • Societal methods of control eg supervision registers, Mental Health legislation etc. • Participation may be a strategy to legitimise unpalatable change eg rationing (Rutter <i>et al.</i>, 2004).