What does social inclusion mean?

Mark Bertram reports findings from his survey of service users, which asked what the term 'social inclusion' meant to them.

> *'Ideas and theories have no ultimate meaning except in relation to individuals' experiences. It is too easy to take reality, turn it into a subject, and then consider it as a subject and not as reality.'* (Linnett, 2006)

The term social inclusion now appears everywhere in economic and social policy. It is promoted as the 'heart of the government's mission' to try and create healthier and fair societies (Cabinet Office, 2006). There is much debate and a range of related guidance has appeared. This can be boiled down to a number of key questions. What does social inclusion actually mean? How useful is it as a concept or theory? And how could it be applied as a policy and practice target?

In the context of mental health services, social inclusion is also being promoted as a top priority – even to the extent that it should become the primary purpose of future provision, and constitute the next phase of reform…

> *'We have to continue to improve community care and break down the barriers that can prevent people from rebuilding their lives…services aim to go beyond traditional clinical care and help patients back into mainstream society, redefining recovery to incorporate quality of life – a job, a decent place to live, friends and a social life.'* (Appleby, 2007)

One of the key questions facing commissioners and mental health services, then, is how is this going to be achieved? Significant shifts needed in the culture, philosophy and practice of service provision have already been identified (Main, 2006). Some NHS trusts have developed social inclusion strategies to articulate how their vision can be implemented. For example:

> *'The principle guiding our work at all levels of the organisation must move away from a primary focus on the reduction of symptoms towards one of enabling people to do the things they want to do and lead the lives they wish to lead. The yardstick of success must be the extent to which the treatment and support we provide enables them to rebuild valued and satisfying lives and to gain/maintain the homes, friends, families, relationships, jobs, social and spiritual opportunities, leisure and cultural activities that give their lives meaning.'* (Perkins & Rinaldi, 2007)

This is powerful stuff. It calls for fundamental change to the way services have historically operated, and chimes directly with what people say helps in a recovery process (Faulkner & Layzell, 2000).

A survey

Across the UK, efforts to facilitate social inclusion will be at different stages of planning and implementation. There will also be varying levels of user involvement within these processes. However, if social inclusion initiatives are to have an effective impact, it is crucial to learn from the insights of local people.

In order to explore what people who use our inner city mental health services really understand by social inclusion, I co-ordinated a survey of over 150 individuals, through one-to-one interviews and discussion groups. This was undertaken within the context of developing a local strategy for our trust. Service users trained to interview people living in acute, medium-secure forensic and rehabilitation wards facilitated 30 individual interviews. Our local clinical

governance department helped with data gathering. We explored two key questions relating to social inclusion, and responses to these are discussed below.

What does social inclusion mean?

Survey respondents were asked what social inclusion meant to them as individuals. Some were quite clear what the term meant to them:

> *'I do not get accepted in most situations.'*

For many, however, the term social inclusion had little meaning. This was particularly evident in responses from people living in secure, forensic and acute wards. For example, typical responses might be 'I don't know,' 'Ask the doctor,' 'Top secret,' or 'Staff have control.' One person said: 'When I took my medication, my family took me off the ward.'

Some thought social inclusion was associated with the government:

> *'Bit of a buzz-word phrase – government-speak – not sure what it does mean. Most people won't.'*

Another person thought it was theoretical:

> *'It's the theory of there being opportunities for people to be involved in society.'*

For others, social inclusion was about their psychological experiences of being in the world. Concepts of self-esteem and sense of identity were seen as key.

There are two elements of social inclusion, which are inevitably intertwined. There is an idea of self-inclusion or exclusion, which is very individual as is a person's DNA. Personally, I believe that inclusion is all about belonging – to take part in society fully, to be needed and to need. However, to be truly included you need to be self-included: ie. believe in your own worth. It is possible to be actively included, but not emotionally (self).

Some people gave examples in which their social designation was a barrier to inclusion because of stigma and discrimination. However, access to employment as a practical step to increase autonomy and self-worth was crucial:

> *'To me, social inclusion means to facilitate the involvement of people like us who are usually left out of the community because of our physical/mental condition or because we belong to a minority. It means giving a chance to those who are usually deprived of opportunities that others take for granted. Social inclusion is particularly important with regard to employment and vocational opportunities because it can significantly increase people's independence and autonomy.'*

In contrast, others felt that social inclusion was not about employment:

> *'Social inclusion is a sheltered work programme, like a carpentry programme, to earn some pocket money, not a proper job.'*

> *'Social inclusion is getting the maximum welfare benefits one is entitled to.'*

Others still associated it with having their most basic needs met:

> *'Yes, sometimes my family takes me home and feeds me.'*

For many, social inclusion was about relationships with others, and enjoyment was seen as central to it:

> *'It's about having a fun and enjoyable life, mixing with others and settling down.'*

> *'Sex and love.'*

> *'More social contact. I am looking for a wife, I would like a housewife.'*

Another theme was the importance of being validated for who they are, and the acceptance of difference:

> *'It's about all groups in society being recognised and included – especially in generic/mainstream services. And should be about people being acknowledged in their own right/in their own groups, not just assimilating into the mainstream.'*

> *'It should be a simple term whereby you are accepted into life, and try to accept all in that life, work, play, enjoyment, money, education, relationships etc. Because it is a very personalised concept, you will get many different perspectives, and they may all have a degree of validity.'*

One elderly person captured some of the personal aspects when he wrote seven pages of an autobiography in response to the survey questionnaire:

> *'My earliest recalls are that of making an entire landscape out of a spread of white sand that I found near my first home, on the edge of a stream. I made roadways, a bridge, and little hills, which I populated with twigs for woodland. Small stones and grit for hedging. Bits of wood and brick for houses. My small figures and animals, cars, a tractor and steamroller had their life there. From time to time wheel barrow marks and adult foot prints messed up my village landscape… But I never thought of complaining… And now I come to think of it, maybe I can recognise that this has*

"I believe that inclusion is all about belonging – to take part in society fully, to be needed and to need."

> *"It is about an individual's activity of daily living, and how they relate to the outside world. It is about bringing the world into a life."*

been a prevailing feature in my life; I tend to excuse others first for all my disappointments. Is it any wonder that I more often than not find myself relegated to the edges – a very real form of social exclusion in which I am complicit?'

In contrast, the response below notes how earning power and status may lead to self-imposed exclusion:

'Inclusion is seldom simple. For example, there are individuals who, because of their notoriety, have to exclude themselves away from the mainstream. They are successful, recognised and financially secure, and yet they need to be "cushioned" from society and therefore are not "socially included". An example of this may be gated communities, television celebrities. But because they have access to funds and notoriety, they can pick and choose the levels of inclusion they require at any one time. Question: is the Queen socially included?'

Can mental health services help?

Survey respondents were asked whether they thought mental health services could help people in the area of social inclusion – and if so, how?

In general, mental health services were seen as having a crucial role in facilitating social inclusion, but services and professionals needed to change their approaches. There were consistent calls to go beyond symptom management and develop person-centred approaches:

'Try and replace the fear with real support and possibilities.'

'Social inclusion is not about disability, symptoms or "treatment management". It is about an individual's activity of daily living, and how they relate to the outside world. It is about bringing the world into a life. The mental health system focuses purely on symptomology, which is in its very nature negative. The whole person needs to be looked at, and the symptoms need to be "put on a backburner". The more socially included an individual feels in a societal way and in a personal way, the more likely they are to grow, find greater independence, and be self sufficient.'

'Help service users to live a productive life, afford them coping mechanisms so they are in control of their own health and life needs. Let them be adults, to make mistakes and to learn life's tricks. Nurture not control. Facilitate not dictate. Listen not tell.'

'Services need to bridge gaps to a world of normality. Opportunities need to be individualised.'

Many people mentioned a process of personal development as being fundamentally linked to social inclusion:

'You have to get faith, trust and confidence, work at it to build things up. Then things happen.'

'More spiritual involvement. Jogging, aerobics, good food. More involvement in sharing, forgiving enemies, exercise. Respect for all religions, staff, psychiatrists, therapists should be united and enlightened.'

Although individual progression, control and access to normality are seen as potential solutions, low self-esteem emerged as a key obstacle:

'Low self-esteem can make mental health service users negative about everyday life in society.'

'The principle causes of low self-esteem are connected to stigma that users suffer from in a direct and indirect way.'

Service users believed that it is the role of health and social care services to try to address these barriers, while acknowledging that there may be limits to what can be achieved:

'Mental health services can't tackle the wider issues… it's too much.'

In terms of practical initiatives, there were consistent calls for user involvement in shaping service provision, and for investment in new vocational programmes:

'Services can help by… providing funding to develop new vocational and training programmes and by increasing real involvement opportunities for users to help in shaping and delivering services.'

Challenges to the system

As I listened in focus groups and read survey responses, it became clear to me that there was also a lot of anger, scepticism and suspicion:

'Social inclusion! That's just a government buzzword that actually means let's force these malingerers back into work and save the Treasury money from the benefit system.'

Some people thought the nature of society, the exercise of power and the processes for managing mental distress were a direct cause of exclusion. For example:

'We're all part of society anyway – like it or not. Social exclusion is about the fact that people are discriminated against, marginalised, invalidated, by people with power over us. And this especially

happens by us being labelled "mentally ill", "mentally disordered", having "severe and enduring mental health problems" etc.'

'It's got to be about society's own vision being big enough to encompass, accept and address the psychological suffering of people, which it is in large part responsible for in how it's organised and what it values. It's got to be about no longer hiding our suffering behind pseudo-medical labels that individualise, internalise and reify the problems. We no longer suffer because we've struggled to cope with a shit deal in a harsh world, but because we've got "mental health issues". And we are shuffled off into the "mental health" ghetto and stupefied with drugs.'

'The service does not help me. I used to have a nurse come and see me, but because of the cuts she doesn't come anymore. My allowance has been cut, so nowadays I have next to nothing. Where I am there is no security. I would like to be in a place where I feel secure. The doctor doesn't listen to me.'

Seen in the light of these critical perspectives, social inclusion becomes more than remedial fixes for tackling social exclusion. People highlighted a need to examine social, political and economic conditions, and construct effective ways to change the circumstances and structures that create exclusion.

Conclusion

The evidence here reveals a range of issues that deserve reflection and action. From a provider perspective, the key challenge will be transforming these insights into initiatives that help people reach their full potential.

For some, social inclusion meant nothing or provoked anger and suspicion. This accurately reflects the understandable pessimism associated with many people's current status and lived experiences. For others, inclusion was a multi-dimensional process involving the self and an opportunity or a goal, to reach somewhere better. One person thought inclusion was being taken home to get something to eat. The multiple meanings associated with social inclusion clearly constitute a vast terrain – like life – full of struggle and possibility.

However, the term social inclusion does not in itself sufficiently capture this diversity, richness and depth of people's experiences. It is clearly not a theory, concept or a thing, and can only be explored, lived and experienced by individuals. A key question then is, inclusion into what? Many people highlighted some disturbing experiences of being included into society – discrimination, social inequality and complete loss of hope. From what people were saying here, the candle of possibility can be blown out by the weather and social inclusion is both highly personal and political. There were calls for extensive social change, but can the social inclusion agenda address this?

In terms of the individual, helping people build self-confidence, develop relationships and gain access to employment was seen as critically important. But social inclusion also meant gaining access to a range of ordinary activities, as well as getting enough money through benefits. The primary principle underpinning any helping process, then, must start with – in an emotional, social and practical sense – where the person is.

We might well ask who is best placed to facilitate social inclusion? Certainly, the evidence from this survey suggests that fundamental changes are needed to the ways in which mental health services operate. People who receive services are clearly asking for increased autonomy in decision-making, and a widening of the types of help being provided – a move toward a person-centred orientation – services that listen, validate and genuinely help people get to where they want to go.

This article is dedicated to the memory of Peter Linnett (1954–2007), a genuine person and an exceptional writer who described truly how to help others.

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