Making social inclusion a reality for people with mental health problems is everyone's business

Anyone who has a life

Social inclusion is a term that has arisen over the past two decades in Europe and its meaning is still contested. The most frequently used summary is: '... a shorthand label for what can happen when individuals or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environment, bad health and family breakdown.'[1] There are three ways in which mental health services can contribute to promoting social inclusion. The first and simplest definition is to see inclusion as access. Within this frame of reference an inclusive organisation is one that ensures all its activities serve the whole community. Hence inclusiveness applies not only to access to services and decision-making around individual users but also to participation in planning and management and access to jobs.

The Social Exclusion Unit focuses on four key areas of people's lives in which social exclusion is particularly prevalent and which have a pervasive impact on all other aspects of individual and collective well being.[1] Everyone, including people who use mental health services, should be able to enjoy a good standard of health, develop their skills and abilities, earn a wage and live a life in the community in safety. Similarly, standard one of the national service framework for mental health[2] demands that all people whose care is managed through the enhanced care programme approach should have a care plan that addresses their needs for housing, employment and leisure.

Within this framework an inclusive mental health service will respond to psychiatric symptoms and offer treatment and a place of safety but will also pay real attention to housing, education and employment. The community mental health team will include, or have direct access to, job coaching services, supported education and leisure, and a strategy that ensures high quality accommodation. Information that is provided to service users will cover all these aspects of life, rather than just health and social care services. At the heart of this work is a belief that people with mental health problems can make a practical and positive contribution to their communities as employees, neighbours and so on – and that these roles are a crucial element in recovery.[3]

The reality for many people with mental health problems is that, apart from professionals and other service users, they have no friends or community. This is why over the past 25 years an international network of people have been exploring strategies for creating a social mix between people who need support and other citizens.[4-6] Within this framework supported living replaces congregated staffed housing,[4] real jobs replace day centres, and friendship with a diverse community of citizens (some of whom may have mental health problems) replaces comprehensive dependence on mental health staff and survivors.

An inclusive organisation that focuses on relationships will push beyond the bald provision of a decent home and job to provide effective support for the development of good networks. Instead of 'whirlpool services' in which people find that increasing contact with psychiatric services means the systematic erosion of contact with informal networks, mental health teams will provide effective support to maintain these supportive and positive networks. Friendships can never be artificially created but there are conditions that nurture friendship, such as respect and reciprocity.[7] The inclusive organisation will be working with others for the development of a tolerant, welcoming community in which diversity is celebrated.

The following articles explore briefly some of these dimensions of social inclusion from the perspectives of disability rights, mental health promotion and acute care.

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This article is a compilation of excerpts from the Sainsbury Centre resource book Working for Inclusion

Right on their side

MS MARSHALL applied for a job as a fingerprinting officer with a police force and was offered the job, only to have the offer withdrawn when occupational health screening revealed her diagnosis of manic depression. In 2001 she won her case to Industrial Tribunal under the DDA and received nearly £20 000 in compensation. She is working successfully elsewhere.

Ms Melanophy, a successful customer services manager in an educational publishing company, challenged her employers after they sacked her for misconduct while she was a psychiatric inpatient. Her performance and conduct had been affected temporarily by a 'high' phase. The tribunal ruled that the employer had discriminated against her and had not followed its own disciplinary procedures. It is quite reasonable for an employer to expect good performance and conduct but not to fire someone without exploring why their behaviour may have changed and what might resolve the situation. She too is now working successfully elsewhere.

Mr Watkiss was offered a senior job with a construction company but the offer was withdrawn after his diagnosis of schizophrenia came to light. He challenged the company under the DDA. The threat of litigation was enough. The company settled out of court, admitting unlawful discrimination, and paid Mr Watkiss substantial compensation.

→ Using the law

Disability rights policy creates significant opportunities for mental health service users. But the opportunities are not being fully grasped. Throughout the 1990s disabled people in general in the UK gained ground in terms of social exclusion. The implementation from 1996 of the first phases of the Disability Discrimination Act 1995 has outlawed discrimination against disabled people in employment and goods and services. People with physical and sensory impairments have begun to find public support for equal rights. But mental health service users have seen the signs going the other way: increased NIMBY campaigns,[8] hardening public attitudes[5] and legislative proposals focused on constraints on liberty. Over the past decade the proportion of people with severe mental health problems of working age who are actually working has consistently remained below 20%: the lowest rate of any group of disabled people.

The comparison suggests the mental health community needs radically to rethink its strategy for social inclusion. As survivor and activist Peter Campbell has written: 'The great irony about service user action in the past 15 years is that while the position of service users within services has undoubtedly improved, the position of service users in society has deteriorated. As a result it is at least arguable that the focus of user involvement needs adjustment.'[9] History suggests that it is unwise to assume that if mental health services are first reformed wider changes will follow. The opposite strategy is much more promising. First, take active steps to enable people with mental health problems to work, raise children and participate in their communities. Once they become more prominent as colleagues and fellow citizens a new spotlight is likely to be thrown on mental health services that are low quality or excessively coercive.

But education alone is not enough, as experience from the World Psychiatric Association's global anti-stigma programme has shown.[10] Legislative measures are needed alongside public education initiatives to place controls on negative attitudes and behaviours. Since the Disability Rights Commission (DRC) came into being in April 2000, replacing the National Disability Council that had no powers of enforcement, it has supported a number of cases concerning employment discrimination faced by people with mental health problems. Indeed by 2001 23% of all DDA employment cases were taken by people with psychiatric impairments. Cases such as those described (left) are beginning to make employers aware that they cannot discriminate with impunity, and that practical ways forward are possible. The DRC actively offers a velvet glove – support to achieve good practice and promotion of the major benefits of an inclusive workforce – but employers know there is an iron fist in the glove, which can give them extra encouragement to listen. Initiatives need to go beyond the naïve, but still common, belief that informing people of how common mental health problems are (one in four) or increasing people's knowledge about mental illness will somehow miraculously result in reduced discrimination. There is no evidence for this belief. The most promising strategy is to combine enforcement of legal rights – the iron fist – with work to change powerful beliefs in public and policy debate, coupled with practical, grassroots initiatives that change the nature of interaction between people with – and without – mental health problems.

Liz Sayce

Mental health promotion

Until recently mental health promotion has been little recognised in debates about mental health. Within the NHS local priorities have been driven by the need to improve mental health services, with a focus on ensuring those who are thought to need medical treatment receive it.

While local authorities have taken the lead in many areas that have a strong influence on mental health – notably neighbourhood renewal – an explicit framework for addressing public mental health has been missing. This means that at a strategic level mental health impact is not routinely included as part of the decision-making process, with significant consequences for the mental well being of communities and the quality of life of people with mental health problems.

Standard one of the national service framework for mental health[2] places mental health promotion firmly on the policy agenda.[11] It requires health and social services to promote the mental health of local communities and to take action to tackle the discrimination and exclusion experienced by people with mental health problems. This provides a unique opportunity to acknowledge that we all have mental health needs, whether or not we have a diagnosis. These needs are expressed and may be met in

families, at work and on the streets, in schools and neighbourhoods, in prisons and hospitals. Reducing structural barriers to mental health and introducing policies that protect mental well-being will benefit those who do and do not currently have mental health problems and the many people who move between periods of mental health and mental illness.

The acknowledgement that everyone has mental health needs is an important pre-condition for social inclusion, notably in the workplace. The alternative is survival of the fittest culture, which makes a few grudging concessions to people with mental health problems, prompted mainly by fear of litigation.

It is a profound irony that many of the 'reasonable adjustments' required under the DDA would benefit anyone who has children, relationships or elderly parents, anyone who has worries about money, alcohol, friends or housing, anyone experiencing bereavement, illness or crime. Anyone who has a life, in fact.

It is often argued that mental health promotion is not relevant to people with mental health problems. This view is being challenged in the face of growing evidence of the limitations of medical models of care. This means rethinking and expanding definitions of treatment to identify what an individual needs to regain or hold on to a life that has meaning for them.[12-14] This engagement with the whole person lies at the heart of social inclusion in its true sense. It is driven by respect, reciprocity, shared decision-making, an emphasis on people's strengths, a belief that everyone can make a contribution and a model of recovery, rather than illness. These values provide a framework against which the culture of the organisation and individual practice can be assessed.

Consultation and patient involvement are fundamental to the modernisation agenda outlined in the NHS Plan.[15] For local authorities Best Value requires widespread consultation on services. Both will require a greater focus on quality of life indicators that impact on how people feel. Given that lack of control and lack of influence are independent risk factors for stress, how people feel about services may be as significant as clinical indicators of effectiveness.[16] There is both an ethical and a public health case for enabling people to influence decisions that affect their lives.

In many ways standard one underpins the successful delivery of the whole National Service Framework.[2] It also provides an opportunity for those working to promote mental health and those delivering secondary care to work towards a shared goal of building supportive services and hospitable communities.

However it is important to recognise that social inclusion is not an intervention or a treatment but a set of values and principles that inform policy, culture, attitudes and practice. While mental health professionals can be a catalysts for breaking down barriers, social inclusion is about landlords and tenancy agreements, job centres and benefits officers, insurance companies, employers, credit unions, timebanks, citizens advice bureaux, primary care, pubs, art galleries, adult education, leisure centres, hairdressers, neighbours and the Independent Living Fund. These require changes in policy and practice across all sectors. The extent to which people with mental health problems are effectively denied citizenship and prevented from enjoying the same opportunities as everyone else will need to be tackled at a strategic level. Community strategies and community safety partnerships, neighbourhood renewal, regional cultural consortia, regional development agencies, regional chambers and regional assemblies – and the numerous other policy initiatives listed (right) – can make an important contribution to the social inclusion agenda if they ensure their commitment extends to users and survivors of the mental health services.

Lynne Friedli and Elizabeth Gale

Acute care

The concept of social inclusion is often not considered during periods of acute care. Social inclusion is about social roles, networks, relationships and communities, whereas acute care often involves time away from communities and networks, social roles and relationships. But socially inclusive strategies must be prioritised during periods of acute inpatient care to maintain the roles and relationships that are so important for recovery.

' ... A period of admission may help to maintain a person's social roles by relieving them of responsibilities and expectations they are temporarily unable to fulfil. However in the longer term admission to a psychiatric ward may lead to erosion of all roles other than that of a mental patient. Lengthy and repeated admissions have been found to lead to smaller social networks, comprising fewer friends and relatives and more professionals and service users.'[17]

Staff who work on acute wards see people only at the point when their mental health problems are most severe. It is important that their expectations do not become tarnished so they fail to recognise skills and abilities and become pessimistic about what a person might achieve. Nothing is more likely to lead to a person giving up than a loss of hope, and it is to this routine under-estimation of potential that 'negative symptoms' such as 'lack of motivation' are increasingly being attributed.

It is essential that staff value every person, recognise their potential, nurture their hopes and identify a way towards realising dreams. From the very first admission attention needs to be given to promoting self-management of problems. This involves enabling a person to monitor their own difficulties and crisis/relapse planning. If a person is able to identify problems early and take the necessary remedial action this can →

National initiatives for social inclusion

Health
Health improvement programmes
Health action zones
Healthy living centres

Employment
Employment action zones
New Deal for Disabled People
New Deal for Older People
Healthy workplace initiatives

Education
Sure Start
Education action zones
Children's Fund
Connexions
Healthy schools programme
Excellence in Cities
Millennium volunteering

Neighbourhoods
New Deal for Communities
Regeneration
Community strategies
Neighbourhood renewal
Local strategic partnerships

Working for inclusion

Working for Inclusion is one of the products of the Citizenship and Community Programme: an 18-month programme on inclusion policy and practice joint-funded by the Sainsbury Centre for Mental Health and the Department of Health and involving a wide range of national agencies and organisations concerned with mental health, disability rights and social policy.

The programme is driven by three specific principles. First, people with mental health problems have been subject to widespread discrimination but have the right to participate in every aspect of community life. Second, inclusion demands that mental health organisations and activists widen their focus from a preoccupation with the reform of mental health systems and join hands with non-mental health, community-based organisations. Third, while mental health services have traditionally focused their attention on 'fixing the individual', services also need to play their part in 'fixing the community'.

Working for Inclusion: making social inclusion a reality for people with severe mental health problems, *edited by Peter Bates, is available from the Sainsbury Centre for Mental Health £25 (£15 for service users and small voluntary organisations) t 020 7827 8352*

→ decrease the disruptive effect on their lives and relationships and so promote their social inclusion. Staff have to be able to trust individuals, to hand over power and see individuals as able and competent rather than passive recipients of care.

If a person is to resume their roles and relationships and rebuild their life then it is important that acute ward staff attend to the things that are important to the service user, even when these differ from what practitioners think is best for them.

An inclusive philosophy and environment are of little value unless they are matched by socially inclusive practices. A social inclusion agenda requires that acute wards address the individual in the context of their life: those roles, relationships and activities that are important to the person. One way of helping someone maintain activities and contacts is to use a weekly diary to record their usual routine before their problems became disabling. This means spending time with the person discussing how they spent their week: who they saw when and where, what they did in the evenings, how often they went out and where. Then, when significant relationships have been identified, ways of maintaining contact can be planned with the person.

The physical environment is important – for staff as well as those who use the service.[15] All too often inpatient wards are depressing and demeaning places.[18] It is vital that the ward environment feels welcoming not only for the individual patient but also for their relatives and friends. The ward team needs to agree the purpose and value of family involvement and develop an ongoing assessment and support strategy that is implemented by all staff, including receptionists, domestic staff, the nursing team and psychiatrists. On admission people should be asked about their friendships and offered help to tell friends they have been admitted: a person's chances of resuming a friendship after admission are jeopardised if they simply 'disappear' from their social networks without explanation.

Given the importance of work and employment in promoting social inclusion, particular attention should be paid to issues of employment or education on acute admission. With a person's permission it may be helpful to make a specific employment plan, check whether the person has sent a sickness certificate to their employer and liaise with the employer to maintain the job. If the person is not in employment or education, or does not want to return to their former job, then employment or training opportunities should be considered during their admission and a detailed vocational assessment undertaken.

Although current priorities and staffing levels in acute settings often militate against socially inclusive strategies, it is often possible to make some improvements, and to adjust priorities within existing resources. The development of inclusive strategies in acute settings could improve services for all involved, resulting in better outcomes for service users and making work on acute wards more rewarding for staff.

Rachel Perkins and Julie Repper

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