

CHAPTER FOUR

Social Inclusion

Overview

Topics covered in this section

- **So what is Social Inclusion and Why Does it Matter?**
- **The Challenge Starts Here**
- **“Don’t Talk rubbish, these tablets won’t hurt you”**
- **My Life as a Social Inclusion Worker**
- **“The Individual Knows Best”**
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Aim

This chapter will provide an insight into what Social Inclusion means from both a professional and personal perspective. It will explore some innovative ways of professionally achieving Social Inclusion and how some of the practices of the mental health system can lead to Social Exclusion. The importance of providing individuals with socially inclusive choices and how this can be achieved with direct payments and individual budgets is also discussed.

Learning outcomes

By reading this section you will begin to understand:

- The definition of Social Inclusion.
- Definition of Social Exclusion.
- How innovative ways of working can induce Social Inclusion.
- How different working practices can lead to Social Exclusion.
- The many benefits of direct payments and individual budgets.
- How to begin to provide socially inclusive services and choices.

So What is 'Social Inclusion' and Why Does it Matter?

by Malcolm Barrett

Well, I don't know about you, but I do have a view about how I'd like life for me and my friends and loved ones to be. Thing is, that view changes depending on how I feel, what's happening in my life, what's going on in the world around me and what my mood's like at any given time. Sound familiar?

So what is Social Inclusion then? Well, I'll tell you what I think Social 'Exclusion' is... I think Social 'Exclusion' is about discrimination, lack of human rights, being prevented from taking part in ordinary daily life by virtue of lack of money, education, work, access to people, places, and things.

So what does it mean to be socially included? The clue is in the word 'Social'. I think it means from a societal perspective, ensuring that people who have been marginalized, discriminated against, or excluded, have greater access and ability to participate in decisions that affect their lives and what they may aspire to do or be. This is about the fundamental human right to have a sense of Well-being, a sense of purpose and to be connected.

In the world we live in there is a lot of talk these days about 'choice'. But to have 'choice' you first have to be 'included'. That means having your voice heard and, more importantly and as a consequence, the opportunity to act on the choices you express.

There is increasing evidence of what can work to assist people in reconnecting to the world... to be included. This can be achieved through volunteering or work opportunities, through access to education or life skills, through access to friends and the opportunity to participate, through choice, in your community.

Frankly, to be given the chance to do what works for you. To have something to engage with and look forward to.

Is this not true for all human kind?

Working in the field of Social Inclusion, as I have for many years, now also leads me to think about what it means to be socially responsible. That in itself is another huge question, but if we want a society where people are not excluded then there are some hard questions we all need to ask ourselves.

For example, what kind of society do we want? What are the burning issues that face us? Who out there cares about those issues? If we care, where does the responsibility lay? What can we do to raise awareness and promote responsibility in the communities in which we live?

It's my view that to end exclusion we need to consider more carefully some of these wider questions.

Changes in the Health and Social system means there is an opportunity to do things differently. The challenge is... do we want to?

If we truly want to empower people then we have to give power up. We have to work harder to work with people and hear and see their aspirations, to support people in the struggle for inclusion. This requires big system change.

This requires powerful advocates. It requires a strong voice from people in receipt of services, strong service user movement.

We need to make good mental health everybody's business. This way we can eradicate the stigma associated with having a mental

health problem, we can feel healthier in ourselves as individuals and as a society.

Is it really too much to expect that a system set up to assist people with their health and Well-being takes on the challenge to work with people's whole lives? To see people as more than just a diagnosis? As being the recipient of 'treatment'?

Through the Social Inclusion agenda there is a fantastic opportunity to do things differently and to lead the way in challenging old practices and beliefs. And things are certainly changing. The recognition that it's not in anyone's interest to have a society where exclusion is acceptable has led to a raft of policy initiatives which, bit by bit, are having an impact on the way people think about what it is to be socially included.

We must stay awake and alert to those changing challenges, and also seek to influence those changes through an individual and collective voice which celebrates success and points the finger at unhelpful practice and processes.

My mood is a little better today after having the opportunity to express these views. I feel connected. I hope you do too.

The Challenge Starts Here

by Chris Rowland

*"How beauteous mankind is!
O brave new world,
that has such people in it!"*
The Tempest, V.i.

I often use this quotation when presenting on social policy around the region. The tempest of the play's title brings vividly to mind the feeling that I, and many of those whom I meet, have experienced working in or using health and social care services over recent years: wave after wave of new initiatives, pilot sites, policy and guidance; stormy restructurings within the health service; health and social care systems confronted with huge cost-pressures; and individual staff struggling to keep their heads above the water of uncertainty about future employment, changing roles, and ever-increasing expectations.

But Shakespeare's lines also capture for me something exciting and important about the present context of health and social care service development and delivery. Look for a moment beyond the rolling seas, and there is an increasingly clear vision, and a clear path being forged towards it. It is a vision which recognises the individual worth of people, a vision of a society which accepts, supports and includes every member within it as having value, and something to offer. And increasingly, there is also a clear path laid out in a developing body of policy and legislation with a focus on putting the individual at the centre of their services through choice and self-direction; a focus on health promotion and Well-being as essential service deliverables; a focus on dignity, respect and equality; a focus on communities, integration and inclusion, where community engagement and building social capital are seen as core to the role of health and social care service delivery.

This is a vision which will be both familiar and welcome to all of us who have a leaning towards the values and principles that have traditionally underpinned social care services especially. But as a policy-driven, whole system change, this represents an important shift in emphasis. It is a change which promotes the importance of social care practice and values, as well as the role of Local Authorities in health service delivery (as increasingly enshrined in, for instance, the recent Local Government White Paper, *Stronger and Prosperous Communities*, and exemplified by the recent appointment of David Behan as Director General for Social Care on the DH Board). There is an ever greater emphasis on joint (rather than "joined-up") working, with joint appointments, shared commissioning arrangements, and single planning processes. And it is not so much a direction away from health service delivery as towards it, perhaps a return to the origins of the NHS, which started life as a health service when all is said and done!

"Our Health Our Care Our Say – The policy context"

A range of recent policy and guidance provides the backdrop to this change. *Choosing Health*, the Public Health White Paper (DH, 2005), outlined key issues that we need to address if we are to improve the health of our population (and not just the obvious ones like smoking and obesity, but also issues around mental health and Well-being), and the importance of recognising individuals' responsibilities in making decisions that effect their lives, as well as their rights to do so. *Improving the Life Chances of Disabled People* (PMSU, 2005) offers a 20-year vision for disabled people, stating boldly that "by 2025, disabled people in Britain

should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society". This will involve challenging social attitudes to disability, and the services which we provide, and the acceptance within the document of a social model of disability (it is not any impairment I may have which causes me to be disabled, so much as society's attitudes and barriers) is an important step towards this. The Social Care Green Paper, *Independence, Wellbeing and Choice* (DH, 2005), began to develop this vision into a set of principles for how and why services might be developed in the future. The title, I think, says it all, but it also contains as clear a description as anywhere of the direction of travel we are following:

"Our starting point is the principle that everyone in society has a positive contribution to make to that society and that they should have a right to control their own lives. Our vision is to ensure that these values will drive the way we provide social care. The vision we have for social care is one where:

- *Services help maintain the independence of the individual by giving them greater choice and control over the way in which their needs are met;*
- *Services are of high quality and delivered by a well-trained workforce or by informal and family carers who are themselves supported;*
- *We provide services with an emphasis on preventing problems and ensure that social care and the NHS work on a shared agenda to help maintain the independence of individuals;*

Through:

- *...[allowing that] the risks of*

independence for individuals are shared with them and balanced openly against benefits.

- Wider use of direct payments and the piloting of individual budgets to stimulate the development of modern services delivered in the way people want;

- Greater focus on preventative services to allow for early, targeted interventions, and the use of the local authority Well-being agenda to ensure greater Social Inclusion and improved quality of life.

Alongside these generic documents there have been key pieces of policy addressing the needs of particular groups of people, whether *Every Child Matters* for children, *Valuing People* (DH, 2001), for learning disabled people, *Mental Health and Social Exclusion* (SEU, 2004), for people with mental health problems, *Reaching Out: an action plan for Social Exclusion* (2006). All drive different parts of the service system reform and delivery, but all with a shared focus on inclusion and Well-being.

Our Health Our Care Our Say – the key themes

And so to the Department of Health White Paper titled *Our Health, Our Care, Our Say* (2006). I describe it to people as the most important piece of legislation for the development of health and social care services in recent years. It develops the ideas in *Independence Well-being and Choice*, and the vision of *Improving the Life Chances of Disabled People*, but takes them further; not only making health and Well-being the business of social care (and wider local authority run services), but also placing social care values, principles and practice at the heart of health service delivery.

The wide-spread public consultation on *Independence Well-being and Choice* showed that people are pleased with the direction of travel of health and social care service delivery, but that they expect more: more personalised services meeting individual needs; greater support for healthier, independent lives; more promotion of Well-being; better support for those with high level needs; and services shifted to local communities. (And this is not, therefore, to reflect negatively on the positive practice

that has been offered before: ten years ago, air-bags on a car would represent an enhanced or added value product feature, but no-one would buy a new car today without them; expectations change and increase!) At the same time, as a society we are presented with some huge challenges: an ageing population, and greater numbers of people living with long term conditions (in itself a compliment to the effectiveness of our health services); more complex family caring responsibilities, but a family and community structure which struggles to support these challenges; as well as (on a more positive note) greater opportunities for service development and innovation (for instance those offered by assistive or pharmacological or surgical technologies).

Our Health Our Care Our Say supports a change of emphasis on how services are offered in the community, around three key themes.

- Putting people more in control of their own health and care, with more choice, and a stronger voice in service design and delivery. (As Patricia Hewitt suggests in the introduction, "All public services should put the person who uses them at their heart. This applies especially to Health and Social Care because all care is personal".)
- Enabling and supporting health, independence and Well-being through better prevention and early intervention services, and underlining the need to tackle health inequalities and improve access to community services.
- Rapid and convenient access to high-quality, cost-effective care, especially for those with long term conditions, or who need it the most.

It goes on to outline a number of key outcomes for successful change within health and social care services. If we get this right we will see health and social care services delivering improved health and emotional Well-being, and improved quality of life outcomes; people empowered to make a positive contribution and having greater economic Well-being; people having greater choice and control over their support; and services provided in such a way as to ensure personal dignity, and with freedom from discrimination.

One of the nice things about working to support this agenda is that I come across very few people who disagree with the principles of it. However, there are plenty of people who are quick to highlight the challenges of making it a reality, and not surprisingly, since to deliver it will require some significant strategic shifts, both in thinking and in service design and delivery. Shifting focus (and funding!) from acute responses to preventative services; from hospitals to communities and care closer to home; from service inputs to outcomes for people and communities; from decision making in Whitehall to local communities of interest; from doing "to", "for" and "with" people to being "led by" people; and from separate performance and commissioning frameworks to more joined up approaches.

Our health our care our say outlines how this in turn will require (on a more practical level):

- Strong local commissioning shifting towards prevention and early interventions, with practice based commissioning in primary care and individualised budgets in social care.
- A shift of resources into prevention, and into community services.
- Allowing variety and contestability in provision of care to encourage innovation in service delivery, especially around the possible roles of social enterprise and the third sector.
- Developing outcomes which apply to both NHS and social care, with aligned performance measures, assessments, and inspection, and aligned planning and budget frameworks drawn together through Local Area Agreements.

So plenty to be getting on with then!!

One of the strengths of the White Paper is that, as well as giving the direction of travel and the underpinning system changes that this will require, it also contains a wealth of details of things that we can / should do to get us there; and importantly, they represent a huge breadth of very different things, cutting across health, social care and community services. Grouping them under four main headings, examples include:

- Helping people to make choices and take control by

understanding their own health and lifestyle better, with more support on prevention and promoting their independence (including piloting a new NHS Life Check, more emphasis on mental health and support to deal with isolation and depression, increased use of Direct Payments and Individual Budgets, and improving information).

- Offering people easy access to help when they need it, and in a way that fits their lives (including new initiatives to support carers, a guarantee of registration onto a GP practice list in their locality, greater information about choosing a GP practice and about what health and local authority services are available in their area, incentives for GPs to work in areas that are under provided for at present, and improved access to GP practices through more flexible opening hours etc).
- Meeting the whole of people's needs and supporting their Well-being and health, not just focusing on sickness or an immediate crisis (including strengthening roles for the Director of Adult Social Services and Director of Public Health, and more joint appointments; health and social care jointly responsible for understanding the needs of their communities and providing the right services to prevent ill health and support independent living; a common assessment framework to ensure less duplication across different agencies and allow people to self-assess where possible).
- Providing safe and cost-effective care closer to where people live (including a fundamental long term shift from hospitals to community facilities and from institutional to home-based care, piloting outpatient appointments in the community for common conditions such as dermatology, and a new generation of community hospitals to provide a wide array of non-urgent services in a community setting).

Our health our care our say: the opportunity and the challenge

It begins to become apparent just what a huge agenda this represents; how it cuts across health and social care service provision, but extends well



beyond this as well; and by implication, that it will require strong leadership across health and social care services and beyond, and ongoing political commitment to realise the changes. But there are some real opportunities for driving change forward at the present time: not just a strong political will, and a body of social policy to back this, but also, and increasingly, systems which support community integration, development of social capital and the reduction of health inequalities. Within the Eastern Region, we have a Regional Social Strategy and Regional Health Strategy which focus on Social Inclusion and the reduction of health inequalities. And at a local level, Local Area Agreements (whose significance is set to increase in light of the Local Government White Paper) drawing together the development aims of local communities, and maintaining a focus on health and Well-being as being in need of support from across social systems.

We have the policy guidance (and the legislation) in place to be able to move the money away from illness-treating services and into preventative, health-promoting community services; to focus on the people most in need; not just improving lives for all but reducing health inequalities; to increase the already positive impact that individualised support (whether direct payments, In Control, or individualised budgets) has had for people; to empower local neighbourhoods and communities of interest; to provide choice and access to services. And we have the technological solutions to maintain support to people (even

at crisis point) within their own homes and communities.

But there are also some significant challenges for us to think about and plan for. As I suggest above, people will say: these are nice ideas, perhaps it would even be difficult to fault some of them in theory...but what about in practice? And that is the central challenge: how do we realise the vision? How do we get from where we are now to where we need to get to? Importantly, we are not starting with a blank sheet for this radical redesign of support, so what needs to change first and where do we start? Change processes are notoriously difficult to take forwards in large organisations (and the NHS is in the top three!), and they take a long time to bed in: How can we change quickly, and change well? How do we change ingrained commissioning behaviour within new systems? How do we change staff behaviour, attitudes and values to put the user and carer genuinely in the driving seat of their life and support system? Can and will systems of health and social care really involve the customer in redesign? And whilst the change is in process, what (or who) might get lost in the process? How will it affect patients and service users? How will it affect staff and impact on service reputation or the good will of communities?

How can we move to a situation of choice and control, and, if we support people's rights to make health promoting decisions, how can we support these to be "rational" (e.g. give up smoking, take preventative action on disease)? And if they don't, are we prepared to carry that risk?

How do we empower the most vulnerable to maximise their health and take control, and what radical change needs to happen in systems to facilitate change for the most vulnerable? What would we need to do differently to make this step change?

And some very practical challenges: how can we join up planning and funding cycles, not to mention information streams and monitoring? How can we generate the evidence that what we are doing is effective? How do we make the shift in thinking from outputs to outcomes, and the metrics based on the actual experience of our customers?

And last but not least, people will ask: how do we take forward the move towards preventative services, especially when there is no money to pump-prime the new services? We are faced with some major financial problems at present, both in health and in local authorities. But perhaps this is the place for us to start, rather than end. In 2003/4 the NHS spent 43% of its budget on people over 65, and social services 44%... By 2015 there will be more people over 65 and many more people living with long-term and life-restricting conditions. These costs will only increase if we don't think seriously now about how we provide services. This is not all about money; it is about quality services for people who need them most; it is about choice and accessibility; it is about health and Well-being; it is about Social Inclusion and social justice. But perhaps, in this case, economics might be an argument in favour of change as well as an obstacle to it!

“Don’t talk rubbish, these tablets won’t hurt you”

by Stephen Corran

Sir Keith Joseph (1971) said: *“The treatment of psychosis, neurosis and schizophrenia has been entirely changed by the drug revolution. People go into hospital with mental disorders and get cured.”*

This quote is a suitable launch pad for my overall view of medication, which is intended to investigate the validity of treating emotional or psychological crises with psychotropic chemicals. This paper will, of necessity, look at the labelling process, which, in my view, essentially possesses a moral rather than medical judgement.

The chemical means to control distress is the first approach to treatment that anyone coming into contact with the psychiatric services will be offered. The wisdom, or not, of electing to become ‘a patient’, and everything the ‘sick’ role implies, is the subject of discussion in the following pages.

We shall look at whether chemotherapy actually works, perhaps considering the following comment: ‘The drugs work, not by correcting some bio-chemical imbalance, but by sedating someone to the point where they are indifferent to their relatives’ hostility.

The purpose of this piece, however, is not specifically to offer a criticism of the system that interprets internal disturbance or social deviation as an illness. I must, though, establish at the outset that personally I hold the understanding of life crises as ‘patterns of disease’ to be completely mistaken. I don’t think so called ‘symptoms’ should be dismissed, but feel that they have a meaning to each individual, the understanding of which would lead (possibly) to eventual healing and personal growth. I strongly

believe, as did R.D. Laing, that breakdown is purposive, and that under the right conditions can be a positive experience. Perhaps it would be too controversial to suggest madness may be a form of internalised ‘journey to the gods’ – i.e. out of oneself. If this ‘trip’ were successfully guided, one should return to a greater level of personal integration. Radically, I could see the madman as a shaman. Clinically, this would manifest as ex-patients helping future patients to go mad!! Rather too unsettling for many, I feel?

As it is, the biological approach is seductive to both physician and patient, promising something positive from the world of science, and all its certainties; the patient not having to feel his/her life is governed by irrational and disordered impulse. We all know the scenario – ‘Oh, doctor, thank you so much. I can’t tell you how relieved I am to know I have an illness. I thought I was going mad!’

It is strange (even after Freud) though, that people fear, even deny, their irrationality, yet, for example, are fascinated by their dreams and avidly read newspaper horoscopes.

The biochemical approach also, of course, removes the blame from patients, as their symptoms are explained away as mere chemical imbalances. People do tend to demand comfortable, non-confrontational solutions.

Before we move on to the labelling process, one of the functions of which will be to determine somewhat arbitrarily the drugs that will be prescribed, I think it would be useful to draw attention to the work of Rosenhahn, an American psychologist who, in his paper ‘Being Sane in Insane Places’, describes how he and his

researchers were admitted to a number of psychiatric institutions. Briefly, at interviews, they claimed they heard innocuous words like ‘thud’ as voices. They were admitted and once on their wards, spoke and behaved absolutely normally. All their behaviour, though, was interpreted within the conceptual framework of psychiatry. For example, one researcher who was making notes was said to demonstrate ‘compulsive writing behaviour.’ All, needless to say, were given the diagnosis of schizophrenia. It is not without interest to note that their fellow patients spotted there was nothing wrong with them!

It is also interesting to note, diagnostically, that some 150 years ago we just had ‘lunacy’. Now, according to DSM IV, there are over 400 sub-classifications of mental disorders. We seem to have reached the point where every nuance in human behaviour can be pathologised!

Rosenhahn coined the term ‘pseudo patient’ after this study, which raises vital issues as to the subjectivity of the psychiatric interview and the social and political bias of psychiatry. Once you have a label, all your subsequent behaviour is interpreted accordingly. To give a psychiatric label is judgemental and stigmatising; it would only be of value if it aided in one’s Recovery. Although, it has to be noted that some people do find their identity this way.

One of Rosenhahn’s observations was of the overwhelming powerlessness one has in an institution. Erving Goffman’s book, ‘Asylums’, drew attention to this and led to the study of the so-called ‘institutional neuroses,’ heralding the gradual emptying of the large hospitals. The systematic loss of identity and heavy

tranquillisation renders people passive, hence easy to control. As we shall see, the chemically lobotomised person is best suited for a life where there is a complete absence of individuality. I use the term 'lobotomy' due to the effect of tranquillisers on the will and the emotions.

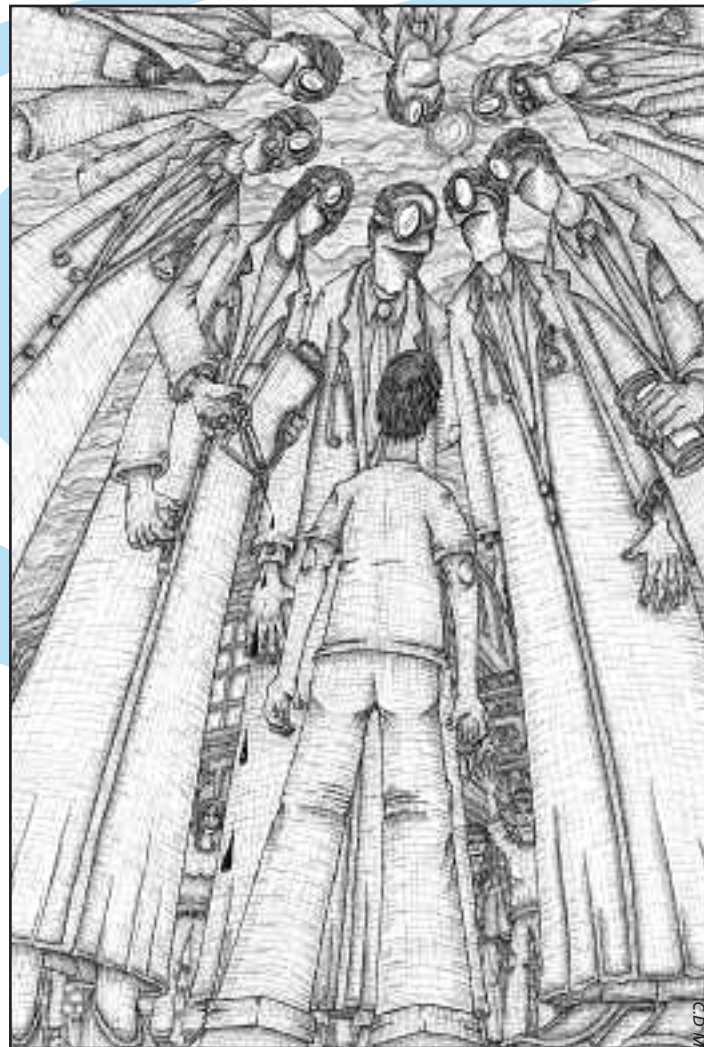
The above also applies, of course, to such establishments as prisons and care homes.

I have briefly touched on how labelling dehumanises and, personally, I tried to subvert this process by turning classification on its head. When I was in hospital we were all given hospital numbers. A friend and I derived great amusement by addressing each other using our numbers rather than our names. The hospital staff just couldn't understand this, which made it doubly amusing!

This loss of self is furthered by the insistence in the interview that you describe the most intimate, personal details of your life. Why? – I never discovered, as no one seemed to act on any information I might offer. This sort of exchange just reinforces one's subordinate role. I have often found that it is an enlightening exercise to turn the tables and ask the registrar if she has a satisfying sex life. The response is usually an education in itself!

It has always struck me that the interview is a very elaborate 'game'. However, there are counter-tactics that can be employed. For example, the following quoted by Laing: *"A young man is being asked if he hears voices – 'yes' he says. 'What do they say' 'they say – "You're a bloody idiot."*

Possible misunderstandings arising from a poor interview can have frightening implications for one's future. I give such an example from my experience with a young, rather wet behind the ears, registrar. During the course of the interview, I had occasion to query something. She suggested a second opinion from the consultant. I had lost two consultants in my previous hospital through death by internal causes, and saw my chance here to test the skills of this person. I replied: 'I am not sure if that would be safe as I have the power to kill consultants!' I have never seen anyone write so much in such a short time! My white lie is preserved for posterity – she



C.D. McAllister

should have questioned me further on this point.

One final example of dehumanisation happened to me recently. I was at an out-patients clinic and told the consultant I was experiencing a certain level of anxiety when in crowded places or new situations. You should bear in mind that, due to my supposed schizophrenia, I have been socially isolated for over two decades. It is hardly surprising that, wishing to re-engage with my community and build a new life, my confidence was at very low ebb. Giving what was frankly an honest explanation of my discomfort, I thought I would appeal to his humanity. However, I was met with a cold stare, told I had 'social phobia' and that he could give me something for it. I felt so hurt, misunderstood, devalued and furious; I vowed to have nothing further to do with psychiatry. The system had robbed me of virtually all my adult life and where had I got? His negativity inspired great positivity in me, but I doubt he had the 'nous' to realise it.

I remember another occasion when my mental health workers once again made me feel bad

about myself. At one case conference they told me (quite incorrectly) 'You're an alcoholic, and a drug addict, among other things'. I was made to feel ashamed and bad about myself (in front of about 15 complete strangers), any guilt was reinforced.

I should now like to move onto the main topic of the paper. I shall deal with this by discussing three main points.

1. What drug treatments are available to deal with 'schizophrenia'.
2. How is each individual prescription, in terms of choice of drug and its dosage, assessed?
3. How responsibly is this treatment carried out?

I intend to illustrate the above by drawing on personal experience of anti-psychotic drugs, otherwise known as major tranquillisers or narcoleptics. These were largely of the neuroleptics group, the first of which, 'Largactil', appeared in the early 1950s; known to its detractors as the 'liquid cosh'. I was prescribed these for a period of over 30 years.

Psychiatric drugs are often given

in combination (known as polypharmacy), in spite of a 1993 paper on high dose prescribing which found fault with the majority of doctors. Polypharmacy is a clumsy and potentially lethal form of treatment which is contrary to official guidelines. I shall draw on an analogy that you should understand. Imagine being given a shot of whisky and not being seen to be feeling any effect. You are then given further shots of gin, rum and vodka. In short, you have a cocktail, all ingredients being essentially of the same type? Bear in mind, "A drug is a toxin with some beneficial side-effects." My personal cocktail, as I remember it, consisted at various times of the following:

- Stelazine
- Largactil
- Melleril
- Haloperidol
- Orap
- Depixol
- Modecate
- Imipramine
- Cipramil
- Epanutin
- Tegretol
- Epilim
- Hemineverin
- Diazepam
- Lorazepam
- Atarax
- Librium
- Buspirone
- Nitrazepam
- Flurazepam
- Temazepam
- Welldorm
- Noctec
- Zimovane
- Nembutal
- Disipal
- Kemadrin

Most recently, I was treated with the so-called 'atypical' or second-generation drug, 'olanzapine.' The effect was initially not as unpleasant as the first group, but it is by no means 'clean'.

The availability of these new 'atypicals' is largely a post code lottery as they are expensive. It is surely wrong that life altering changes to one's treatment regime should be made not by council decisions, but by economic ones.

In 1999, the annual cost of the average medical daily dose was estimated as follows:

- Largactil £23
- Depixol £300
- Clozapine £1800

However modern the pharmaceutical approach may be, in comparison to earlier physical

treatments such as hydrotherapy, insulin comas, ECT or psychosurgery, I maintain it is just as hit and miss. Each individual's response in terms of absorption rates in the gut and the blood/brain barrier is different. It must be stated that there can be no blanket rule in prescribing.

Malpractice in such an inexact science has been evident to me in many scenarios over recent decades. For example, on querying my dosage and asking if my blood/drug levels could be monitored, I was told this was impossible.

Side Effects

I should now like to consider the immense issue of side effects. These arise via the effects of the drugs on different systems on the body. I shall deal with them in no particular order. The major noticeable SE is tiredness, as this amusing anecdote demonstrates very well:

Synopsis: Epsom Derby Day Sandwiches/orange squash. Brown envelopes with lunchtime meds. Hour later L. Piggot is coming in on historic win with Shergar – whole world watching. 10 yards away from the finishing line, small circle of snoozing people on the grass!! Events of the world wide pass you by on Melleril!

Not only did I feel extremely tired, I virtually always experienced a dry mouth, and, paradoxically, excessive salivation to the point of drooling. The latter is socially embarrassing and the former causes you to take constant sips of water, necessitating frequent trips to the loo, but when you get there, sometimes nothing happens, as another side effects is difficultly in urination. I have known someone who had to be catheterised for this reason and steps had to be taken to deal with what came to be called his 'obsessive drinking behaviour.' I frequently became constipated; a friend of mine also, to the extent that he bled once and was subsequently examined for suspected haemorrhoids.

A massive side effect leading to inevitable embarrassment, hence not often aired to staff, is sexual dysfunction. This covers everything from varying degrees of loss of sexual interest, difficulty in getting or maintaining an erection, to complete loss of ejaculation. I remember mentioning this to my senior

registrar when starting a relationship with a young 'schizophrenic girl'. This lady doctor replied: "I wouldn't worry. It's probably for the best. You have 46% chance of having a schizophrenic baby." Our physical relations were at first literally 'sleeping together'! She certainly never needed a 'headache'!

It was, in fact, the same girl who asked her senior registrar why she had to have Depixol. This doctor replied "Don't worry 'why' dear. It's doing you a power of good. We give it for something with a long name most of us can't even spell". Apparently 60% of patients in the late 1970's were not told why they received anti-psychotics.

I will concede that I am writing of a time when you were placed in the 'sick role' and staff managed your life for you.

However, returning to side effects, I had a sensitivity to sunlight. The slightest exposure gave a sensation like insects crawling under the skin. Denial of this experience was apparent when I was given UVA/UVB treatment for eczema about 15 years ago, despite my protestations. It was agony. One may also be liable to be insensitive to extremes of temperature – possibly leading to stepping into a scalding bath (interpreted as self-harm!). I used to watch patients smoking cigarettes right down to their fingers without apparently noticing the burns.

I experienced weight gain and breast enlargement (especially on Olanzapine). This, (especially the first), is damaging to women's self image. I am not prepared to discuss the issue of breast size! I constantly had symptoms of pseudo parkinsonism, i.e. tremor with stiffening and weakening of the muscles. You can picture trying to lift a glass (too heavy), move it to your mouth (too rigid) and, if you're lucky enough to get it there, you've been trembling so much you've spilt half of it down your shirt! Again, extremely socially embarrassing. Common, also, are gyrating thumbs – known as pill-rolling.

I used to shuffle around and had a wooden mask like expression. It often isn't so much the psychiatric condition that marks you out, it's the visible effects of the drugs. I remember going into a shop a few years ago. The woman

served me and said to a friend of hers as I was leaving "there goes another one from the funny farm". Such comments are deeply hurtful, yet if one can summon the strength to realise it, you may be confident that such a level of mindless ignorance reveals that the main problem is not yours.

Woody Allen wrote: *"Cumulative side-effects took their toll on my perception, and when I could no longer tell the difference between my brother Morris and a soft boiled egg, I was discharged."*

Another predominant side effect is a tremendous inner restlessness. One has to constantly move to dissipate what seems to be an ever increasing pressure inside one's limbs.

If you can imagine lying in bed, trying to sleep, but you can't because your legs have a life of their own – they thrash from side to side – it is actually painful to try to keep them still. Compulsive movement helps. I used to call the marching on the spot 'the phenothiazine shuffle'. I doubt, though, that it's a sequence you'll see on 'Strictly Come Dancing'! Incidentally, this restlessness may be wrongly interpreted as agitation or anxiety, leading to increased doses of the offending drug.

An extremely nasty effect is known as 'oculogyric crisis.' My eyes would roll upwards so my visual field became the ceiling. I had absolutely no control over this. What I dreaded most was the accompanying feeling of a terrifying foreboding which would sometimes last a few hours.

Incidentally, on three occasions I was prescribed combinations of drugs to treat both physical and psychiatric conditions with potentially lethal effects; Namely, I was once cheerfully told, 'sudden death syndrome'. It was this that killed Sean Walton at the Ashworth Hospital in 1990. High doses injected in combination can prove too much for the heart. The coroner's verdict is normally 'death by natural causes' – a whitewash. For many years my pulse ran at 110/120 beats per minute. No one raised an eyebrow, even when my body temperature was found to be up by about 1 degree.

I should also introduce the contentious issue of 'iatrogenic illness.' It is questionable whether a drug, that in treating condition

A causes a secondary condition B, should be used at all in clinical practice. For example, use of anti-psychotics can lead to jaundice and potentially fatal cardiac arrhythmias.

At various times I have had an inability to cough or swallow. The inevitable outcome of this is, of course, inhalation of and choking on food. Not being able to swallow would drive me up the wall at night. The only way to make the reflex work was with a mouthful of water and I had to try and sleep sitting up as it made the process easier. My respiratory system was also affected. I suffered from sleep apnoea, meaning a cessation of breathing at night. When something made me realise I was not breathing, there would suddenly be an enormous, noisy intake of air. This conjures up a picture of everyone's perfect pest in the dormitory at night. The silence of the early hours would be interrupted by the sound of thrashing legs, mattress squeaking with a jack-in-the-box who periodically gasped with the desperation of someone fighting for their last breath. Not a recipe for peace.

It was commonplace, before the emptying out of the big institutions, to see wards full of men and women grinding their teeth, grimacing horribly with tongues sticking out. It was often pointed out to me that I was doing all or any of the above, although I did not realise. My arms would sometimes jerk.

Although, on reflection, I seem to have painted an extreme picture, one should bear in mind that my body suffered a non-stop 26 year bombardment of extremely high doses of medication, often given in combination. Individuals' physiological responses differ widely too, as I have established. I think it is a marvel that this essay is not reaching you from the afterlife!

Now we come to what may be changes in gait and posture. I remember once, on an insanely high dose of Stelazine, finding walking almost impossible. As I went along, I began to lean backwards to the point of almost falling. This must have presented an amusing picture. Imagine a figure proceeding hesitantly down a bustling street leaning stiffly backwards at an angle of 30 degrees. It occurs to me now that John Cleese might have liked to

borrow this one!

Every ten yards or so, I had to stop, straighten up and lean forward almost to touch my toes. I knew I must be drawing some attention, which, of course, accentuated my feeling of oddness and of being under observation. When I reported this difficulty, admittedly the dose was lowered, but I know that these socially crippling effects were viewed as secondary to the supposed benefit to my mental state. Indeed, I would go so far as to venture that side effects were understood to be regrettable, although an inevitable part of one's life. One of two wiser nurses admitted to me privately that this was no cure; my symptoms were merely being masked.

Yet another side effect that I experienced was grimacing and twitching. These are both a sign of Tardive Dyskinesia; irreversible neurological damage.

I am told that this damage, often only really noticed when the drug is withdrawn, is best treated by resuming the drug! Tardive Dyskinesia is a proven fact, though most doctors in my day were in denial about it. Far from being the panacea one was led to believe, in 1992 it was estimated that some 500 million people world-wide had used major tranquillisers, of which 86 million had succumbed to Tardive Dyskinesia permanently. It has been said:

"If schizophrenia were less debilitating, narcoleptics would probably be withdrawn on grounds of toxicity."

Any benefits of a drug should be examined in the context of its use. This group of drugs might better be described as a chemical bull in a china shop – unpredictably interfering with a wide variety of bodily systems. The drug clozapine was referred to in an episode of the X-Files (when used with temazepam) as causing "widespread unpredictable behaviour".

It should be a serious concern that a drug cannot 'cure' mental disturbance - so we must ask whether achieving nothing of real value in the long-term, yet causing actual neurological damage, these drugs should be used at all? They are still over-used and their role is over-emphasised, as I found when I telephoned the ward in Epsom where I had received most of my

treatment. I spoke to a young staff nurse, who, when having explained myself, commented – "You sound very well". "Yes, I am extremely well". "You must have been taking your medication!" This came from someone 100 miles away who had never met me and, I suspect, wasn't even born when I spent time on the ward. I never cease to be astounded by such reliance on a form of treatment that patently only touches the surface of the problem.

I think now it is realised that social problems cannot be cured by a pill. However, I feel the judicious use of medication to calm someone and bring them to a rational appreciation of their problems, to a point where they can be 'reached' and empowered to access organisations that can help get their life back on track again, is valid. Really, as the reasons for breakdown are multifold, so are the ways back to wholeness. We are predominantly social beings with many different needs.

It has recently hit the headlines, I am glad to say, that we have an immense problem with the prescribing of anti-depressants to children. Not before time, it is being suggested that more 'talking therapies' should be introduced. I would extend this to alternative or complementary therapies, where the mind/body relationship is viewed more in terms of harmony and integration. We all have the potential to self-heal if we can learn to utilise the right methods. If a tablet can make us feel better, we, through changes in our lifestyle, can effect the changes in chemistry naturally. Often, the list of side effects is longer (and more discomfiting) than the symptoms the drug was designed to control. As Eli Lilly famously said: *"A drug is not a drug if it does not have side-effects."*

I am sure we all shrink with horror at the thought of a 5 year old on Ritalin or Prozac. Consider this possible scenario. A troubled and hurting child has a one-off incident, which, if mismanaged, escalates to medication, appointments within social services, finally possibly being taken into care. I have known several people who have slipped into long-term psychiatric 'careers'.

How sad it is, also, to see elderly

people who were determined to stay independent, being admitted to hospital and being 'broken' by medication, as they were becoming a 'management' problem.

I am led to understand that there is no known deficiency of serotonin in depression. I never had my dopamine levels assessed. Incidentally, did you know that it is said an injection of blood serum from a 'florid' schizophrenic will precipitate a 'normal' person into a psychotic episode? Also, that if you give LSD to someone florid, it will have no effect whatsoever?

Returning briefly to Tardive Dyskinesia, in addition to the physical manifestation is a mental sluggishness called 'encaphalitis lethargica'. Personally, I noticed a monumental inability to think straight or to feel anything (also known as 'tardive dementia'). If I complained about side effects, I would get the following sort of responses:

"Don't talk rubbish. These tablets won't hurt you." "Your so-called side effects are attention seeking". "Oh it's all part of the illness." "Let me reassure you, there are no long-term effects from these tablets." (The best comment on high doses came from a fellow patient): "I wonder how much blood Stephen has in his Largactil stream!"

Many years ago, after a failed attempt to give up chemotherapy (which lasted 4 months), I was threatened with section 25 if I did it again. It seemed that the medical staff cared more about control than one's quality of life. I should mention, in passing, the abuse of psychiatric drugs in the punishment of political dissidents. It is an interesting paradox to find substances that were intended, and I would happily concede this, for the alleviation of suffering, being so commonly used to cause it. One has to conclude that in the hands of man, anything can be a two-edged sword. The ability to split the atom comes to mind.

On the subject of dosage, for a good 10 years I was prescribed a dose of Modecate, 4 times the maximum recommended by the BNF (this type of prescribing is known by the lovely expression 'megadosing'). In fact, I remember, one morning, there was slight argument with the practice nurse. She called in my GP who said (as if I wasn't there),

"he doesn't normally cause us any trouble, give him another 100 mgs". So I had 6 weeks dosage in 5 minutes, having had 4 weeks worth the week before and the prospect of the same in 7 days time.

It was, incidentally, the same GP who refuted all my insistent claims that I was over-prescribed. I might add that my CPN did likewise. He also kept me away from psychiatrists, who, as he put it, would 'tip the applectart'. If you are compliant and fairly quiet, nothing radical in your treatment will ever happen.

This does raise questions as to the value of so-called 'maintenance therapy.' I accept that relapse rates are lower when medication is continuous, but not significantly. Surely, it would be better to enjoy a quality of life and perhaps to risk an uncertain future. It is interesting to note that the overall outcome of 'schizophrenia' has not improved since 1954 (introduction of Largactil). One registrar revealingly said to me: "Stephen, you improve or worsen despite your medication!"

Over 10 years prior to 1989, I had had varying dosages of Depixol and Modecate. I daren't try to assess how much oral medication I have taken. To me, it is no wonder I have little sense of internal cohesion, and experience a loss of memory and a lack of ability to think straight. If I had claimed such mega-dosing was a conspiracy to keep me quiet, any outburst would have been regarded as a symptom of my paranoid state. It is, however, a truism that even paranoids have enemies! Psychiatry is full of such contradictions. I am reminded of the person who says he feels very well, who is then told that such a statement means that he is actually very ill. I don't deny this may be 'clinically' true, but we are caught in a linguistic web, and, like a politician, your psychiatrist will be good at manipulating words.

I will finish this section by noting that my newly-appointed support-worker was told not to be astonished at the grey/purple discoloration of my complexion, due merely to the extremely high doses I was being prescribed. I hadn't even noticed this in the mirror – presumably because my vision was so blurred!

To attempt to move beyond a

more medical approach, which is what most service users and survivors want, we need to view ourselves as complex beings who relate to the world around us in many ways; the relationship between mind and body is very subtle. I don't believe that we are closed systems in which things happen in a simple chain of cause and effect. Our environment reacts on us and changes us, as we affect our environment.

To treat disjunctions in such a relationship (i.e. life crisis) as diseases raises social and ethical questions. One might ask why, for example, depression/anxiety and ADHD are on the increase? We can look for answers in stress at home and in the work-place, dysfunctional families and relationships, poor diet, and lack of exercise for example.

New ways of working: A different mode

It is regularly requested that safe places to go through periods of distress are needed, places that do not intervene medically. Probably the high reliance on physical treatments reflects a lack of community support/counselling/housing/opportunities for work etc.

If medication has to be used, it must be done with informed consent. Often, when one is first admitted to hospital, it is in a state of extreme excitement and, although I have given the impression of being anti chemotherapy, I have often been glad to be slowed down, both physically and mentally, in order to get some rest. I do think there is an over-reliance on it though.

It is at the point when one is quiet enough to be receptive that different approaches should be suggested. At the time of my various hospitalisations, things were 'done' to and for me. The valuable contribution psychiatry could make would be to aid the distressed person to piece together his/her internal jigsaw and evolve to pursue their lives in as fulfilling a way as possible.

The patient's charter states:
"You have the right to have an explanation of any proposed treatment including any risks involved in that treatment and any alternatives, before you decide whether to agree to it. You can expect to be told what treatments are available other than medications."

Our distress must be taken seriously and we must be listened to. There is often much unresolved anger which needs to be channelled, not suppressed.

In conclusion, I feel the most important contributions psychiatry could make to improve everyone's lives would be to boost confidence and combat loneliness. It would be a move away from medicinal control to social care. I have often felt that the most crippling side effect of the estranging conditions called mental illness is the isolation and pain of loneliness. It is more responsible for the 'revolving door syndrome' than the 'illness' itself. Many times, on readmission, I have heard people say: "How nice to be back here with all of you to talk to", a very sad and telling comment on our so-called society.

We all need the respect and love of others, to be given hope and to find value and meaning in our lives, through a sense of belonging. We need essentially quality of life.

Fostering the above would, I feel, be TRUE SOCIAL INCLUSION.

My Life as a Social Inclusion Worker

by Paul Tyler

Social Inclusion

'Social Inclusion' have been key words for the last few years and have been the basis for promoting change at a high level, but what does Social Inclusion actually mean at grass roots level?

My name is Paul Tyler and I have worked for Cornwall Partnership NHS Foundation Trust for 10 years, the last 4 years as a Social Inclusion Worker. What follows are some examples of the work that I do alongside two colleagues within the Recovery service. None of it is rocket science, it is common sense and, hopefully, will help to recognise basic rights that society often takes for granted.

The most important person in the work that we do is the individual, who, for whatever reason, feels/is excluded from society. Initially, I will spend time with an individual, explaining how I can help, what he/she can expect from me and hopefully build up a level of trust and respect. I always treat others as I would expect to be treated, which helps to build trust and mutual respect. During this time people are encouraged to complete a Social Inclusion Questionnaire, which helps to identify needs in areas of a person's life, including education, employment, leisure and housing. This also helps the individual to identify the most important thing to him/her at that time and gives me the starting point for my work. An example of this is an individual who said what he really wanted to do was go abseiling. One week later he went abseiling, and then he opened up about his hopes for the future, how he needed help with his housing situation and would like to look at employment opportunities and how his finances needed attention. I and the staff at the Recovery unit were then able to work with him to sort out his housing and finances. I then

referred him to an employment placement service who were able to use their skills to help with the employment. One of the things I get asked about the abseiling is 'What about the insurance and the risk?' As far as I was concerned, we used a reputable outdoors adventure company to facilitate the training and checked that they had indemnity insurance. At the end of the day, it was a member of the public accessing an activity in the same way as anyone else would.

When looking to meet needs, the aim is always for access to mainstream opportunities; however, this is not always possible initially. Some people have been excluded for a number of years and it would not be fair to send someone off to college or a work placement in an environment he/she was not comfortable with. One of the ways we tackle this is through stepping stones towards mainstream. Currently, we run various courses in partnership with Cornwall College, including Horticulture and Art courses at the Eden Project and basic skills courses at Selwood House



(Recovery unit). The horticulture course is now into its fourth year and is available to anyone who applies as a volunteer at the Eden Project, but the majority come from the mental health services. This course has led to some students enrolling on mainstream courses, others volunteering at Eden outside of the college times and, recently, an individual gaining enough confidence to apply for and obtain employment with a support provider. The basic skills course at Selwood has recently started and already I can see an increase in motivation, self-esteem and confidence. Hopefully, this will lead to people attending mainstream opportunities as the barriers to learning start to reduce.

These opportunities have come about through myself and my colleagues being given the time to build links and network with other organisations. We facilitate quarterly network meetings (Whole Life Community groups), which give organisations the opportunity to share ideas and good practice, and also the opportunity to work together on projects that will help to meet the needs of individuals. As a mental health specialist provider, we are not a housing expert or a leisure expert or an employment placement adviser, so we need to utilise the expertise that is available in the community as anyone else would. We will not raise awareness and promote inclusion for individuals unless we work in partnership.

Social inclusion is the responsibility of the whole community and will not be attained or maintained without the involvement of the whole community. Myself and my colleagues have made a start in Cornwall and it is making a difference to the lives of individuals, but there is a lot more to do.

“The Individual Knows Best”

by Robin Murray-Neill

Introduction: background to direct payments and foreground to Personal Budgets

Direct payments were introduced in April 1997 following a long campaign by disabled people and their allies. This campaign centred on the belief that far better results could be obtained if individuals had control over the resources used to pay for the support that is provided for them. This belief was based on the fact that many individuals experience traditional services as restrictive, and feel they often deny the individual rights and aspirations of those who use them.

Direct payments are a means by which individuals can be given control over the resources that would otherwise have been used to pay for services to be provided to them. To date, tens of thousands of people have benefited from this opportunity to determine how best, in whole or part, to meet their own social care needs. Direct payments have provided compelling evidence that support based around the individual is not only effective in meeting support needs, but can actually transform the lives of those who decide for themselves by whom, or by what means, their needs for support should be met, and when, how and where would suit them best.

“The freedom that direct payment gives me is immeasurable. First and foremost it gives me control... I employ staff of my own choosing, who are available when I need them most. They follow my wishes and are not bound to distant, rigid policies to which I have had no input. And they help me with the areas of life that I see as priorities for me, at that particular time, rather than being restricted in the

tasks that they can do.”
“...provides me with the support and confidence to live my life as I wish to live it, rather than being constrained by fear, lack of confidence and low self-esteem. I now live in my own home, hold down regular employment and have friends who do not need to worry about also being my “carers”. I go out independently, do voluntary work with people with mental and emotional support needs, and have learned how to trust, albeit a cat! Third, it acts as a form of mental health promotion and maintenance, rather than being part of all too familiar “crisis intervention” process, which, in my experience, has come too late to be a very positive or empowering form of help.”
(Heslop, P. (2001) Direct Payments for people with mental health support needs in The Advocate, May 2001).

However compelling the evidence, the reality has been that comparatively few, (currently still less than 5%), of those who use community care services have actually been able to use direct payments, and there remain huge variations in access to them, both depending on where a person lives and which type of services they use. Many people are simply not being offered direct payments as an option when they should be, and even when they have been, many people's experience has been of protracted delays, staff uncertainty, or being told they are not eligible to receive them.

Thus it is both the success of direct payments, and the limitations imposed on access to them within the current community care system, that has led to the more recent bringing together and implementing of ideas and evidence as to how the whole care system could be

adapted to provide the same level of choice and control to all. The work on designing a new system (generally known as ‘self-directed support’) to enable anyone receiving support in whatever form (direct payments or provided services) to have the maximum degree of choice and control over how their needs are met, has been led by *In Control* since 2003, and given further impetus by the 13 Individual Budget pilot sites funded by the Department of Health since 2006 (www.individualbudgets.csip.org.uk). Two recent developments are of particular interest: the publication by *In Control* of a discussion paper on mental health and self-directed support, (Brewis, R. (2007) A Choice and a Voice, www.in-control.org.uk) and the announcement in Putting People First (HM Govt. Dec 2007) that for social care, individual budgets are to be introduced as ‘Personal Budgets’.

Direct payments (as we currently define them) are not being replaced by Personal Budgets, as is often supposed, but will remain one way of receiving an Personal Budget. Effectively, the system is being remodelled to reflect the aspirations of those who campaigned for so long to bring direct payments into being.

The next part of this chapter has been edited from a conversation with one of the book's contributors. It reflects what I have learnt from a wide variety of people over many years, and is dedicated to the memory of two of those people, who have and still do both inspire and inform my understanding: David Brandon and Phil Miller...

What role does choice have to play in Recovery/Social Inclusion?

It depends what we mean by

choice! And as there is so much said about it, we need to remember it has many meanings, and is not always beneficial in itself. For example, if you give me 100 options to choose something to eat from, I'm not likely to get through many from the list before I say 'that'll do!' I'm giving up, because there's too much information and therefore 'too much choice'. However, if you tell me that as I'm hungry, here's my bowl of semolina with lemon curd, which I would dislike intensely, that would be the opposite of having choice. So I would like to have as much information as I need at that particular time. Ideally, it would be best to start by saying, 'what would you like to eat!' But of course, I may need some information I don't already have in order to make a decision. And whether I do or not, and what type and amount of information, will change according to the subject, my knowledge of it, and my circumstances at that particular time. If, a few years ago, I had been offered a computer and was asked which one I wanted, and perhaps been offered the choice of a basic word processing one, or another more advanced one, and perhaps a top of the range one, too, I'd very likely have said, 'I'll try the first one, and then, if I have any problems, I'll come back to you and try another one'. But now, forward a few years, I have my laptop computer and act as if I can't live without it, and I have programmes for this, that and the other, and I'm far clearer about what level of choice of functions I need, because, with experience and knowledge, my understanding has changed, and so my desire for choice in that respect has expanded.

We need to be aware that there is no formula – that the biggest thing that we're going to have to escape from is people's unending need to be told what 'the model' is; whether that be 'the model' for 'choice', for 'services' or for 'Recovery'. People need to remain sensitive to principles, rather than get lost in the search for watertight policies and procedures to follow. Training often concentrates on procedures, when actually it's the principles that people need to get right first. If you understand the principles, you will be able to react to people in a natural, relaxed and constructive way, and you'll be able to interpret the procedures constructively.

So, choice is a complicated thing,

because it's about what is important to the individual, and the element of choice will vary. For example, in the 1920s when cars first came out, people weren't so bothered that there were only a few standard colours, because actually having access to this new means of transport was of paramount importance to people. These days people say 'I would never drive a yellow car,' or, 'I wouldn't be seen dead in one of those!', which reflects the extent to which people's initial satisfaction largely with the benefit of a particular innovation becomes influenced over time by style and fashion.

Choice is essentially about having the power to say, 'this is what I would like, this is what is important to me'. Even if you change your mind, you have got yourself further along the line; you have found out that a particular decision wasn't a good choice. In life, we learn by going along, doing things. Making decisions can be a bit like tacking up a river against the wind in a sailing boat. Some choices won't get you any further ahead, but it is still better than being taken out of the river, and put into a canal (which might represent some people's experience of entering the mental-health system) which someone else has dug out for you, and suddenly you don't have that chance to tack along in the direction you want to – you go off in the direction they have prescribed for you.

What does inclusion mean - to individuals and service providers?

The job of service providers is not to define inclusion and then apply it to individuals, just because this is the way round that we have produced all our services in the past. People who are supposedly expert in their field, have decided what is best for 'poor, unfortunate people', who need guidance from their 'betters.' Instead what we need to do is say, 'hang on a minute! If we are all equal citizens then should we not all have the opportunity to act equally and of our own volition, so far as is reasonable in relation to each other? Surely it is not the job of people who are paid to be supportive to define what people want, but, instead, to help people define what they want, so it becomes facilitating, rather than an instructing role?'

So what does inclusion mean for

everyday people? My answer is service providers need to find that out for each person; there is no general answer. We can give some *general principles*. For example, a person who is able to do something that other people in that society are enjoying the freedom to do, could be said to be reasonably well-included in that particular respect. However, a key issue is that people should decide the extent to which they wish to be included, and to have the choice as to whether to be included in particular activities.

For example, where I live, I don't take part in much of what goes on around me, so whilst I live in a specific location, say hello to the neighbours, I don't take part in any of the events that take place around me. Now I don't feel that I'm not included by the local community, I just don't want to take part. If I wanted to join in, I could. Other people, however, might say, 'he's a bit excluded, he doesn't have many friends where he lives'. So whose version do we choose?

It is fair to say that some people, if they spent years in a very isolated setting, might find it difficult to get to know people, so perhaps they could develop skills to help them be less isolated. I think there is a matter of making a careful judgement: you ask people, and you give them the reasons why they might benefit from that sort of support, but you don't tell them that they need that type of support, when they don't think they do. It may well be that because someone excludes themselves by choice, we feel that we have failed them in some way. Actually, we might be allowing them to be free, if that is what they want, and if that is how they find they can cope with their life.

It's about finding out how people can set the scene for what's most important to them. I think that inclusion, in a sense, means being able to access things, rather than necessarily actively doing things. We have different areas or 'domains' of inclusion, such as employment, leisure, social networks, by which we measure inclusion, but there are real limitations, and some dangers, in judging how included any one person is by these means. Each person will have their own sense at any given time of what level of engagement with these various aspects of life is right for them. This is true for

everyone, but normally it doesn't come into question.

Partly, it is because these measures are based upon majority expectations of life, but also, when people start to be involved in services, their life becomes a lot of other people's business. Because our mental health system is rooted in the paternalistic, hierarchical, 'doctors know best approach', (which has been democratised to 'professionals and other staff know best!') knowing the right answers for other people in times of difficulty can become identified as the distinction between 'staff' and 'patients' or 'service users'. We need to start to relate to people on equal terms, in the sense that 'I have some skills that might be of value to this person, let's find out what it is that I can offer. What's important to them?'

Our system can actively disregard what an individual knows is best for them and insist, instead, on making its own 'scientific', or 'objective' judgement of what is actually the case for the person in question. When someone identifies a difficulty and the benefits of it being resolved, they can find it simply doesn't fit with what our system has to offer them. And then the 'expert' interpretation comes in, translating the difficulty into terms that the system can deal with and for which they have been prepared by their training. This is a significant problem, as the expert can often be the main person offering support to the individual.

This is why, when we talk about Whole Life approaches, we are really talking about a most fundamental change in the way services provide support to individuals and the thinking behind it. This is where the promotion of direct payments and the more recent progress towards Individual Budgets is so important when considering terms like Recovery, choice and Social Inclusion, because the roots of direct payments are quite different from the traditions and development of the system within which they are available.

What part do direct payments and Individual Budgets have to play in Recovery, Social Inclusion, and Whole Life – for individuals and service providers?

The roots of direct payments are

from disabled people determining how they want things to be, not other people thinking 'this would be a good idea for them'. In fact, direct payments themselves are simply a means to achieve an end, a way to bring far greater choice and control to people within the community care system. Essentially, direct payments are about transferring (either in whole or in part, depending on the individual's wishes) the resources that would have been used to provide arranged social care services directly to the individual, so they can decide how to use the resources to best meet their needs. Arguably, this is a far bigger change than the move from having a system centred on very large institutions to the one of 'community care' which we have at the moment. In that first 'deinstitutional-isation', we moved location but didn't fundamentally alter the principles. It was and still is, at its heart, a hierarchical, institutional, system, although it has been modified to a degree. We moved from 'Doctor knows best' towards 'Professional knows best'. But this is not real change! Our current system is based on the classification of people into groups, by virtue of their diagnosis, and then spending large amounts of resources trying to best determine what this group or that group of people need, then purchasing services on their behalf and fitting each person into the support purchased. This is possible to accept because our system has created a pre-conception that, because people belong to a particular group, the science and the research says they have this or that type of need. In other words, you are fitting people into the services you have already created; moulding your understanding of them and your vision of what they can achieve to suit the services available to them!

The new type of approach says you start with the individual, and work with them first and foremost as an individual. You accept that they might have the same impairment that other people have but they are not necessarily part of a 'group' with those other people. Rather, they might be part of a group with people where they live, or of people who are interested in what they are interested in, or a group of people who have the same trade or profession as

them, or a family group. Or they might not seem to fit, or wish to fit, into any identifiable group.

There is no rational basis for saying people in an 'impairment group' will be the same as each other, but that is exactly what has been assumed, and it is something that has become a common perception throughout our society. Talk about 'disabled people', and many people's response might be: 'those poor people, they have to use wheelchairs because they can't move about and they can't do normal things like we can, they have to be looked after by specialists.' The disabled people who developed the principles of Independent Living turned that notion upside-down, and said, 'whilst an individual might have a particular impairment, which might mean they are restricted in doing certain things, that does not mean they are not just as able as other people in other ways, and may be more able in some ways than other people, with or without impairments'. So we are not talking about 'disability' as opposed to 'ability', but we are talking about every person having a different range of abilities, which means having an impairment is just one aspect of an individual's life, not an absolute determinant of levels of 'ability'. This led to a redefinition of disability, one which shifted the emphasis from personal characteristics to the external things which prevent people from being able to live as full and equal citizens.

Re-defining disability means changing the equation from 'impairment = disability', to 'impairment + barriers = disability'.

In the former equation, impairment is the problem, and lack of opportunity and achievement are seen as an inevitable personal tragedy. In reality, a person's impairment may have a significant impact on their style of life, but it's not the be-all-and-end-all. So, when you recognise that there are barriers that lie outside of you, then suddenly there is something you can do about them. Your situation is not inevitable and inescapable. The focus of the problem shifts from characteristics of the individual that may not be possible to change, to wider society – to things that can be changed and are not the responsibility of the individual.

"People with mental health problems can regain the things they value in life regardless of their diagnosis or symptoms. This requires more than medical treatment, it requires a positive response from society to accommodate individual needs and differing contributions."

Social Exclusion Unit (2004) *Mental Health and Social Exclusion: Social Exclusion Unit Report, June 2004.* London: Office of the Deputy Prime Minister.

There are different types of barriers: 'attitudinal', in the way that people assume things about you because you have a particular diagnosis; 'physical', such as if you have a physical or sensory impairment and simply can't access places you would like to go to; and, thirdly, 'systemic', which means that the way our society operates prevents some people from having the same opportunities and choices as others. For instance, people in certain circumstances are separated from society because people believe it's 'in their best interests'. Once you have created 'places' for people within a care system, people will be found to fill them. The system feeds itself, and has an appetite for people. It is well documented that places in the country with lower levels of in-patient accommodation utilise more community-based solutions. The way we design the systems for supporting people influence the ways in which we perceive people 'need' to be supported.

If we were to start from scratch, the 'care system' could be totally different for many people. Rather than 'taking up a bed in hospital', a person in crisis might, as part of their support planning, remain at home getting extra help from their friend down the road, or from their chosen Support Workers. Another person might take themselves off for a break, with support as necessary. This is not fanciful, there are already examples of it happening. We are certainly not talking about eliminating the mental distress that people experience, but, rather, about recognising that we have previously had a very narrow view of what responses are effective and have undervalued the expertise and abilities of those who are experiencing the distress. People using direct payments commission their own 'services' – such as support worker,

employment and leisure activity services. With the introduction of Individual Budgets these opportunities increase. Those people who want to hold the resources themselves will be able to choose direct payments and use them to access the support they think will best meet their needs. For the other people, they will know the resources available to them but will be able to design and put into place their support plan without having to receive and manage any money, as it can be held by others and support provided as the individual directs. We simply don't know the detail of what this will look like until we start asking people how they want to do things.

In a sense, the move to a system of self-directed support, a system in which Individual Budgets can work, will be an adventure, a journey of discovery between us and the individual. We have the capacity to support people and they are going to tell us how to use that capacity. That is an essential difference from our current approach.

What do direct payments/ individual budgets contribute to Social Inclusion and a Whole Life?

Direct payments and individual budgets are purely mechanisms, or ways in which you give the resources to people who can then decide how best to have their needs met. The essential difference between a direct payment and an individual budget is as follows. Direct payments are available within the current community care system, and involve a sum of money being given to someone so they can purchase services that meet their social care needs – e.g. building confidence, looking after their home, providing themselves with personal assistance. These needs have already been determined as part of a CPA assessment where a care plan is drawn up, often without a lot of input from the individual concerned.

The difference with individual budgets is that the current community care system will change how it operates, allowing a person to identify what resources they are entitled to before they decide on their 'support plan'. This means the person can work out what they want to use the resources for. They do the planning, after they know how much money they

have, and do that planning with whoever they choose, before presenting it to the care co-ordinator for discussion. How this can best work in practice is still being investigated with 5 of the 13 Individual Budget pilot sites, including mental health, and In Control having published a discussion paper. The voluntary organisation, 'Together', have also recently produced a DVD looking at the experiences of people using an Individual Budget in mental health.

Once a 'support plan' has been agreed, the individual can either receive the resources as a direct payment, or look for people who can provide them with the support they want and arrange for this support to be paid from their 'budget' by the person who is holding the money for them. This might be the local authority, the Trust, or another third party. The role of the organisation becomes that of meeting individuals' requirements. If a particular provider doesn't fulfil the requirements of an individual, they can (depending on what is available, of course) choose somewhere else. So it becomes, not finding the money to staff a unit that can look after people, but finding the money to meet people's needs; what each individual wants. This means that instead of organisations being contracted to provide 'x' number of places, or 'y' type of service for 'z' number of people, they will be offering a range of different supports and each person will choose which combination of available support and services they want.

However, the number of people receiving an Individual Budget is comparatively small. It should increase considerably over the coming few years, more so in some areas than others. But for many people, the work to promote direct payments within our current care system will remain important, as the mechanism for giving resources into individuals' control is about the promotion of the choice and control necessary to achieve independent living, which is itself about 'Recovery' and 'choice', and regaining a Whole Life. *"Independent Living is about the empowerment of disabled people and their ability to control their own lives. It is not the name of a particular service or provision but should be the objective of services and provisions, and the*

furtherance of Disabled People's human and civil rights... a concept that is relevant to all disabled people, whatever their impairments... Coventry Independent Living Group (1996)

Direct payments should already be available to a lot of people using mental health services. However they are not being made available. Part of the reason for this is that people working in services can't understand where direct payments fit into their service system. This is because direct payments come from an entirely different origin to our existing system. They are actually the result of the failure of the current system to meet many people's needs in ways acceptable to them. They are a concept developed by the people who use services, not by the people who provide them. In this respect, direct payments are just one part of a fundamental change. When we are faced with something completely new, we generally try to understand it by fitting it into the context of our jobs, the system we have come through, our lives – what we know and understand of what has happened before. But something that comes from an entirely different understanding than ours requires us to step back from what we have become used to thinking, and to try and look at it from a different perspective; that of the people who have traditionally been described as the 'recipients of care,' rather than as the 'architects of support'. Working within very established and complicated service systems, this seems to be something that is proving very difficult for people to do!

What is your vision for Direct Payments?

Earlier on, I suggested that we are moving into an era where the fundamental principle on which we base our support to people is that 'the individual knows best'. It is about who should be deciding the path of a person's life, who should say what gives their life meaning and purpose, what their aspirations and enjoyments are. This should not be the care system, which has previously fitted people into others' ideas of what is best for them, but should be the person themselves, and all our work should be to support people by following that principle, not

ignoring it, or saying that it isn't practical.

There are already a great many people who are now in employment or other activity which they were told in the past could never happen. Such negative predictions limited people's aspirations, confidence and opportunities; it knocked the stuffing out of them. Having a job is essential to many of us, to feeling fulfilled and an essential, valued member of society. Yet collectively, as mental health workers, we have, at the same time as reaping these benefits ourselves, been part of a set up which has had quite the reverse effect on the people it exists to support.

The thing that has kept me so enthusiastic and keen, is not so much giving people money, but the reasons behind giving them money. It is people themselves who will use these resources. It is people in the past who have often had support provided in an injurious way, who can now use it to liberate themselves from the difficulties they may have had. It is essential to continue to raise both the awareness of, and the availability and accessibility to direct payments, as a means by which people can take far greater control of their support arrangements. But it is also essential to recognise that direct payments are not available to everyone. Some people are excluded from receiving them and they do not suit everyone. The system of Self-Directed Support, which makes Personal Budgets and soon Personal Health Budgets, possible, can offer all people the chance to realise this level of control. Getting them right, ensuring that they are introduced in accordance with their origin, essentially the struggle for equality by people drawn into the 'care system', must be a priority for the next few years. A priority that should be led by those people themselves.

THE REAL WORLD

By C.D McAllister

'The doctors know best, they're the professionals, im better off in their care'



'But they don't seem interested in hearing what I have to say'



'Down that road is my local pub and I bet my friends are there right now'



'Should I tell them id like to leave?'



'Would they listen to me? probably not!'



'I haven't been out for so long that im getting nervous. Still ive got to do this at some point so it may as well be now, who knows I might even have fun'



'I think its time I had a change of scene'



'But I may still need their help'



'Ok keep calm and remember, these are your friends'



'My friend Jim tells me about his new motorbike in enthusiastic detail'



'My other friend Mike tells me about his holiday plans his new job affords him'



'im getting some ideas myself now, I feel safe in good company'



'I think im going to be alright'



END.