

Social Inclusion - a framework for evaluation

By Peter Bates and Julie Repper

Over the past decade, there has been increasing recognition of the disabling effects of social exclusion. Government policy has explicitly linked the work of different agencies (housing, environment, health, social services, the church...) in the 'Social Exclusion Unit' set up to combat the ill-effects of 'social exclusion', which it defines as:

'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 environments, bad health and family breakdown'. (Social Exclusion Unit, 1999)

Sayce (2000) provides a more precise definition of social exclusion that draws attention to the interactive relationship between impairment and social role. Although this refers specifically to mental health problems, it can be applied to all those who suffer marginalisation and discrimination as a result of impairment - whether it is emotional, cognitive or physical:

"... the inter-locking and mutually compounding problems of impairment, discrimination, diminished social role, lack of economic and social participation and disability. Among the factors at play are lack of status, joblessness, lack of opportunities to establish a family, small or non-existent social networks, compounding race and other discriminations, repeated rejection and consequent restriction of hope and expectation."

As these relationships have become recognised, many organisations have incorporated goals to combat social exclusion in their core purpose, and there has been a welcome upsurge of interest in strategies that strengthen communities, increase social capital and support individuals to live as valued members of a democratic society. Whilst goals and strategies are an important part of the change process, evaluation is needed to drive that change forward. To date however, evaluation has failed to realise its potential. Here we have set out a framework that we hope will provoke rigorous thinking about how to evaluate an inclusive effort.

We developed this framework in consultation with members of the *Inclusion Research Network*, an informal group that shares an interest in increasing opportunities for people who are at profound risk of being excluded. Most members of the network work in mental health, learning or physical disability services, but the group is not exclusive to these labels. For the *Network*, inclusion in society means full access to mainstream statutory and post-16 education, open employment and leisure opportunities alongside citizens who do not bear these labels. The group concentrates on those people who, along

This article is published as Bates P. and Repper J (2001) Social inclusion – a framework for evaluation *A Life in the Day* Vol 5, No 2 pp 18-23. This article is © Emerald Group Publishing and permission has been granted for this version to appear here at www.peterbates.org.uk Emerald does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from Emerald Group Publishing Limited.

with their allies, need to make focused effort to achieve inclusion. This effort consists of a two-pronged approach of simultaneously re-shaping the community and providing one-to-one support to the individual.

A search of the literature suggests that progress is confined to isolated pockets. For example, *Circles of Friends* have been used to support children in mainstream education, rather than diverting them into the local special school (Newton and Wilson 1999). When it comes to evaluating this activity, one researcher asked family members about their satisfaction with the project (Whitaker et al 1998), and another examined the pace of learning of the non-disabled pupils who shared the classroom (Bunch 1997). While the same principles might apply to an adult entering open employment (family members could support or sabotage, and co-worker productivity could increase or decrease), we know of no studies that have examined these variables. This led us to develop a framework that attempts to describe all the variables that might be captured in an evaluation.

We hope:

- inclusive projects that are planning an evaluation will use the framework to consider which variables are relevant to their purposes.
- readers who detect missing elements in the framework will contact us so that future versions can be more comprehensive.
- to develop a version which makes detailed reference to the evaluation instruments that have been utilised in other studies.
- to identify gaps where evaluation tools have yet to be developed.

Ethics and philosophy of evaluation

We start with the fundamental question about what the evaluation is for and who owns the work. Whilst traditional science has promoted randomised controlled trials and outcome-based research, this is beset with problems in the field of inclusion. Existing outcome measures simply do not reflect the complexity of inclusive endeavours – which take place with both the individual and her/his multiple communities.

The multi-faceted nature of work with any individual to achieve their personal goals requires individually tailored approaches that are difficult to specify for the purpose of comparative experimental research. Besides, in an area that is explicitly about inclusion and empowerment, we inevitably favour emancipatory research - an approach that empowers people. Such collaborative methodologies have the advantage of drawing on the skills and experiences of all those involved, in both the development of strategies and their evaluation. Inclusive approaches are in their infancy; it is only by working with those providing support, influencing local cultures and those receiving it that they can reach their full potential. Definitions of success vary according to perspective: service users, carers, service providers and commissioners all have different ideas of success and these must be taken into account in planning and undertaking evaluation.

Participatory action research is one example of such a co-operative endeavour. Case study research, using different types of data collected by and from different 'stakeholders' is another research approach that is consistent with reflecting the views of all parties (see Robson, 1993). For individualised outcome data, personal goal attainment scaling is a method of assessing the achievement of individualised goals (Ottenbacher and Cusick, 1993). The Strategies for Living project has recently promoted the employment of mental health service users as research staff, and convened a forum for user-researchers (Faulkner 2000). An increasing number of projects share the design stage of the evaluation with service users, employ users to undertake the evaluation, glean evidence from service user accounts, and involve users as co-authors and conference presenters in disseminating the findings.

But where do we actually start?

In the following material we have chosen to begin with the person who needs support to engage in a community opportunity. In doing so there is a possibility that readers will conclude that the entire problem lies with the person who needs support, rather than the environment. In reality, all the factors that we list are interdependent and none is more or less important than the others. Perhaps we should have begun with an examination of the 'site of support' rather than the 'focus person'. But we had to choose where to cut this wheel and roll out the circumference into a story line with a beginning, a middle and an end. So we began with the focus person for the sole reason that this seemed to us to be the simplest place to begin, the clearest way to open up a subject that can become complex.

Despite the considerable research literature on social inclusion, we are still know very little about what works. This means that the field is full of untested hypotheses. The ideal clear-headed evaluator will use the following criteria to test each assumption that she or he makes. However, many of us in the real world are less clear-sighted. We live with working hypotheses and use them to select environments that we anticipate will be successful sites for inclusion. For example, we guess that a company that respects all its staff will be a good place for a person who needs support to work. As a result of this (untested) hypothesis, we use the criteria to pre-select suitable workplaces and reject others. Practitioners are likely to work in this way, but also deliberately question and test these hypotheses from time to time.

The remainder of this article consists of five major headings that together form our framework for evaluating inclusive projects. Under each heading we have set out a number of questions or issues that could be the subject of formal evaluation.

The focus person

When a person is supported to attend a mainstream school, enter open employment or join the dominoes club at their local pub, we can ask some questions about the person themselves. In order to obtain a baseline measure of their need for support, we may wish to explore the person's skills, attitude, self-esteem, communication, social network and relevant history and ambitions. We can ask what support they expect to receive in the mainstream setting, such as the number of hours a jobcoach will work with the person. Support in other settings will be relevant too - the amount of medication or frequency and duration of hospital admissions may reduce when the person moves into a valued role in the community.

As participation in the community-based activity continues, there may be a change in the person's level of skills or difficulties. For example, daytime exercise may improve sleep, reduce the disruptive impact of voice-hearing and improve a sense of well-being. Specific landmarks may be passed in the community setting, such as the person obtaining a contract of employment, formally registering as a member of the group, or obtaining a qualification. New friends and associates may appear in the person's network. The number of attendances, output, earnings or learning gained will give a sense of the person's degree of engagement with the activity. For example, some supported employment schemes log the average hours worked per week, wage rate and tax paid by the focus person.

Finally here, it is worth noting that the adoption of valued community-based roles may not have a uniform beneficial impact. For example, some jobs are so demanding that stress levels increase, diet deteriorates, and friendships are eroded.

The site

Prior to the start of the community opportunity, support staff will have worked with the focus person to identify suitable activities, locate an appropriate setting and assess its suitability. An assessment of the site will include an initial consideration of the fit between the environment and the person. In addition to physical and sensory access (ramps, induction loops, adequate lighting and so on) the social and organisational environment needs to be considered. Attitudes, policies, practices, communication networks and appraisal/feedback mechanisms are all important. Do teams have some degree of self-management and are the views of all participants in the setting valued? Is bullying rigorously opposed and are conflicts effectively resolved?

Asking these questions at the site may provide some clues to the focus person about whether s/he wants to participate here. It may also provide indicators of successful placements that inform future inclusive work. Monitoring the site over time may well show that the presence of the focus person has led to changes in policies, practices or attitudes within the organisation.

The new community

This section examines the characteristics of the group that the focus person is trying to join. Social and demographic indicators may be relevant, as well as some knowledge of the history of the group. For example, a mainstream school that has welcomed children with mobility problems may be less fearful about playground accidents than a school that has not done so.

More importantly, the attitudes, values and knowledge of the particular community will affect the initial experiences of the focus person. Repper and Brooker (1997) found that people with mental health problems experienced a higher level of discrimination in, 'established communities, deprived and saturated areas, family centred communities and areas with no previous contact.' It is important to actually evaluate attitudes, rather than make assumptions. For example, if a person is hoping to join a faith community, then one congregation may connect disability with guilt or evil while another will focus on the precious humanity and gifts of each individual.

Some inclusive projects offer training to community audiences, including an assessment of attitudes before and after training. One might also expect that attitudes, values and knowledge will change as the focus person becomes well known within the setting. A deeper exploration of the group might include values and attitudes about disability in general or a particular kind of disability. The extent to which peers know and trust each other, the way in which they respond to newcomers and their sense of affiliation with the setting will all impact upon the inclusive effort. In addition, it may be possible to identify and influence some key opinion-formers who will have a disproportionate impact upon the overall attitude or culture of the setting (Repper and Brooker, 1996).

Finally here, some concrete measures of productivity or learning by the co-participants was referred to in the introduction to this article. For example, the reliable attendance of a supported volunteer may spur other volunteers on to keep faith with their commitment to the shared voluntary work.

Family and friends

While there are many good reasons for paying close attention to the focus person and the new setting, other people can have a powerful impact upon the success of the inclusive effort. Some researchers have concentrated upon relatives and the potential for the service user to have a negative impact upon their quality of life (the 'family burden' experienced by the 'carers' in this hypothetical one-way relationship). Whilst we recognise the reality of these findings, we also note that people who need support can be strongly valued by their non-disabled family and friends (e.g. Nelson et al 1992, Newton et al 1995), and that encouragement from loved ones can make all the difference to the success of a placement.

It would be possible to include a range of indicators that tell us how family and friends are affected by the inclusive effort. Satisfaction and quality of life will

be an issue for all family and friends and the general health of some people, especially older family members, may be important. There may be some exchanges of support that are also relevant. For example, the parents may be rising earlier on 'real job' days to provide a wake-up call, but the new job also means that the person can pay for board and lodging.

Brokers

The last group of issues in this framework considers the people who hold power over the inclusive effort. This may include health and social care staff who can make an initial referral; specialist brokers, such as vocational guidance staff or a volunteer bureau adviser; or policy leaders in each setting, such as the Occupational Health physician. These individuals have the power to initiate a potential opportunity, give reassurance to the person directly managing that inclusive environment, or bring the arrangement to an end.

The wider political context has a strong impact upon brokers. For example, jobcoaching agencies might have experienced a rapid increase in the number of opportunities on offer following the launch of the Disability Rights Commission. In addition to formal changes in the political landscape, softer changes may also have a serious impact. For example, a minor revision of the funding formula for college courses can have an amplified effect upon the opportunities for people who need learning support. Of course, brokers will have a range of attitudes and values alongside everyone else, it would be useful to measure their attitudes along with those of other parties.

These five headings provide a basic framework for thinking about how to evaluate an inclusive effort. No single project could attempt to measure all of these items, but careful thought about the purpose of the evaluation may lead to a selection of the relevant factors. In addition, some tools are already available to assist in the measurement of a number of these elements. We hope to build on this framework with an index of these instruments and make connections with colleagues who are working on a similar agenda.

References

- Bunch, Gary (1997) Inclusion: Recent Research Toronto: Inclusion Press.
- Faulkner, Alison and Layzell, Sarah (2000), Strategies for Living London: The Mental Health Foundation.
- Nelson, G., Hall, G.B., Squire, D., and Walsh-Bowers, R.T. (1992) Social network transactions of psychiatric patients. Social Science and Medicine 34, 4, 433-455.
- Newton, Colin & Wilson, Derek (1999) Circles of Friends Dunstable: Folens
- Newton, J.; Olson D. and Horner, R. (1995) Factors contributing to the stability of social relationships between individuals with mental retardation and other community members. Mental Retardation Vol 33 p 383-393.
- Ottenbacher, K.J. and Cusick, A. (1993) Discriminative versus evaluative assessment: Some observations on goal attainment scaling. *The American Journal of Occupational Therapy*, 47, 349-354
- Repper, J. and Brooker, C. (1996) Attitudes towards community facilities for people with serious mental health problems. *Health and Social Care in the Community*, 4,5,290-399
- Robson, C. (1993) *Real World Research: A resource for social scientists and practitioner-researchers*. Oxford: Blackwell Publishers Ltd
- Sayce, L. (2000) *From Psychiatric Patient to Citizen. Overcoming Discrimination and Social Exclusion*, London: MacMillan.
- Social Exclusion Unit (1999) What's it all about? *Cabinet Office Website* (www.cabinet-office.gov.uk/seu/index/faqs.html).
- Whitaker, P., Barratt, P., Joy, H., Potter M. and Thomas G. (1998) Children with autism and peer group support: Using circles of friends British Journal of Special Education Vol 25, No 2 pp 60-65.