

Reviewing measures of social inclusion

Introducing the paper

This paper was written by Peter Bates with the help of the *Inclusion Research Network* in 2002-3. Few network members have research experience, and no-one was funded to undertake a literature search. As a result, the paper needs a considerable amount of further work. Whilst it has many flaws, the structure (discussion, tables showing which measures cover which aspects of inclusion, questionnaire and an annotated bibliography) appears to offer a useful resource.

What do we mean by social inclusion?

One starting point is to make a distinction between the individual's sense of inclusion and Government definitions. An individual approach might ask people for their own priorities by asking a question like, 'What would most improve your life?' The respondent might say money, a job and friends, and these items can then become the goals against which that person's inclusion is measured. The Key Indicators section below offers some ways forward if the person happens to answer in this way. If they say 'not having to work' then the indicators have to change entirely, and the Key Indicators only work as a set of Government definitions imposed on the individual.

What is inclusion?

1. Access to specific services.
 - a) Empowerment (including self esteem, mastery, information and consultation)
 - b) Participation in design and review of services delivered to self and others
 - c) Users employed in services
2. Standard of living – a fair share of the benefits of modern society.
 - a) Income
 - b) Housing
 - c) Employment
 - d) Education
 - e) Healthcare
3. Relationships – diverse roles, relationships and connections.
 - a) Social networks
 - b) Social capital

- c) Respect and positive attitudes of others (absence of stigma & discrimination)

Key indicators for social inclusion

The aim of this section is to introduce an 11-question interview schedule that has been devised to provide key indicators for mental health agencies that are striving to support the social inclusion of their service users. They are based on the assumption that people with mental health difficulties should be supported to achieve the same access to these life opportunities as other citizens and therefore a comparison between the scores achieved by a population of people using mental health services should approximate that found in the local population.

These indicators attempt to meet the following criteria:

- They relate to the specific life domains that form key components of a socially included life. Most of these life domains form a context where people could become known and build social contacts and identity.
- They use the minimum number of questions to obtain a broad overview – ideally only one or two questions in each life domain. The questions are tightly defined so that people have no difficulty in understanding what behaviours are included and excluded from the count.
- The questions ensure that life domains are mutually exclusive, so that behaviours that score under one heading are not double-counted elsewhere.
- Most of them are precisely copied from established surveys or measuring instruments and therefore comparison data is available from the general population to help interpret the findings.
- They embrace the diverse lifestyles of people with long standing mental health difficulties.

The eleven questions are set out below in no particular order.

1. How many hours a week do you usually work?¹
2. How safe do you feel walking alone in your neighbourhood during the daytime? (very safe, fairly safe, a bit unsafe, very unsafe, or do you never go out alone during daytime?)²

¹ Question is from Census 2001. The Labour Force Survey counts those aged 16 or over who do at least one hour's paid work in the week prior to interview, or has a job that they are temporarily away from (e.g. on holiday) is in employment. Also included are people who do unpaid work in a family business and people on Government-supported employment training schemes. In the quarter May to July 2002 the employment rate for all persons aged 16 and over was 63%.

² The question is from General Household Survey Social Capital Module Appendix B. The Northern Ireland Health and Social Well-being Survey found that twice as many people who felt unsafe reported

3. Do you see any of the following people at least once a week, on average, mother, father, sibling, adult child, other relative and best friend.³
4. In the last fortnight have you attended an adult education or night class course?⁴
5. Are you currently working towards a qualification?⁵
6. In the past 12 months, have you given up time for charity or for local groups?⁶
7. In the past 12 months, have you been involved at least once in a religious group, club or organisation apart from attendance at events to mark births, marriages or deaths?⁷
8. Which of the following descriptions most closely matches the place where you live? (1) roofless or night shelter, (2) short term accommodation. e.g friend's floor or bedsit, (3) accommodation unsuitable or poor quality, (4) accommodation could be better (5) good accommodation, no worries about rent or security.⁸
9. In the last twelve months have you ever found yourself more than two months behind with your rent/mortgage?⁹
10. In the last four weeks have you participated in any sports, games or physical activities other than walking?¹⁰
11. Do you go to the cinema these days? ¹¹

feeling depressed. GHS distinguishes walking in the daytime from walking at night, unlike the NI study. I assume that feeling safe stands proxy for neighbouring – is there any evidence for this?

³ This question is from the British Social Attitudes Survey. 'Best friend' is the respondent's own definition. This question excludes those without the relative or friend in question and those living with this relative. In 1995, BSA found these percentages to be 49%, 40%, 29%, 58%, 35% and 59% respectively. Every indicator had fallen since 1986. Data is available from the Data-Archive for a fee. Have these scores been aggregated? Is there any more recent data?

⁴ The question is from Health Survey for England. Active Communities also found that, in the last 12 months, 12% of people were involved socially at least once in groups, clubs or organisations in relation to education for adults. Labour Force Survey may have some data.

⁵ This question comes from the DfES. In 1997, DfES found 15.3% of the population of working age were doing this. Which particular survey did this come from?

⁶ This question comes from the Scottish Household Survey that found this was 26%.

⁷ This question comes from the Active Communities survey and they found that this was 18%.

⁸ This question comes from the Avon measure. It appears to be the only questionnaire that includes the roofless and night shelter options. Comparison data is not available at present. However, as the Avon measure is one of the 4 measures currently being piloted for use by mental health services, this deficit should be remedied for mental health populations shortly. This indicator really needs to be replaced by one that can be normed against the general population – perhaps data from the English House Condition Survey? A question on security of tenure would probably be most relevant to inclusion.

⁹ This question comes from the British Household Panel Survey Wave 10, Cover Sheet, Question H39. Data is available from the Data-Archive for a fee. Can ONS or NIMHE get hold of this data without a fee? Has ONS drawn conclusions from this question? Is there survey evidence of a link between debt and mental distress? Can rent debt stand as a proxy for a lack of disposable income?

¹⁰ The question comes from the Office for National Statistics – but which survey in particular? They found this was 45.6% for people aged 16 or over. The Northern Ireland Health and Social Well-being Survey found that twice as many people who were sedentary reported feeling depressed compared with those who were 'above sedentary'. How does the NI study define 'above sedentary'?

Dangers of key indicators

There are many hazards associated with numerical indicators, including:

- Undue preoccupation with these targets can distort health and social care interventions. For example, including cinema attendance (rather than museums, libraries or the local pub) may result in service users being coerced into going to the pictures, rather than doing what they want to do.
- While national averages provide a reasonable starting point for comparison, they take no account of local variations. For example, a rural area might not have access to a cinema.
- Social inclusion is also about the personal meaning of activities to the participant, and these indicators take no account of this important fact. While the majority of people enjoy seeing their relatives from time to time, this does not mean that a particular person will do so.
- There is a temptation to add further quantitative data in order to enrich the picture. This is unwise. It is best to find out what is happening by looking at these service-centred indicators alongside person-centred approaches, such as personal accounts by service users. These eleven indicators are quite sufficient to give most agencies a substantial agenda for action for several years to come. Only when most of the indicators are showing that service users are included in these life domains should service seek to substitute new indicators for those that show success.

Designing a research project

While this paper has offered a set of key indicators, this is a long way short of a research project. The following items need to be borne in mind prior to establishing such a project:

- 'Nothing about me without me' is the slogan of many user advocacy movements and this serves to question the value base that underpins many research projects. People who use mental health services can be partners, or even in the driving seat in deciding what should be studied and how, in piloting and collecting data, reviewing and interpreting findings and in dissemination. Stickley and CUES are the only instruments that we found that approached this ideal and both focus on subjective perceptions and satisfaction.
- Equalities issues need to be borne in mind throughout the design phase. Myers et al (1998) note that many attempts to study social inclusion have failed to address issues of gender or ethnicity, despite

¹¹ ONS found cinema attendance was 56% of those aged 15 and over. Is there a composite measure for arts and culture? These activities are more about use of community amenities with existing friends, rather than opportunities to build new social networks and relationships. Other available questions overlap with sport and education domains.

the fact that the meagre evidence that is available suggest that these factors influence how people experience exclusion and inclusion.

- Sampling. Few surveys and research methods work with everyone, and it is worthwhile to consider who might be left out by the chosen method, and to remedy this wherever possible. None of the surveys that are reviewed here have made extra efforts to glean data from people with major communication difficulties or those with restricted understanding of conceptual issues. The Census 2001 provided versions of the questionnaire in large print, Braille and most European languages.
- The Social Model of Disability suggests that disability is a feature of the social and architectural landscape, rather than a product of the individual. Thus a wheelchair user only becomes disabled when someone asks, 'does he take sugar?' or builds a staircase. An inclusion project may be focused upon changing attitudes towards people with disabilities and noting the ways in which host organisations adapt their premises or systems to include everyone, but most of the research studies and surveys described here measure the individual, rather than their environment. Exceptions include the Department of Health survey on opinions about mental illness and McDonald (2002).
- While 'objective' data may have the attraction of being unambiguous (for instance, a person is either in employment or not), it lacks the component of meaning to the individual. We might know if the person has a job or not, but we do not know what that job means to the person. In contrast, Ottenbacher and Cusack have developed 'goal attainment scaling' as a way of giving numerical value to the progress people make towards meeting their own goals.

Collecting data

There are a number of ways of collecting data about inclusion, including

- Diaries. The UK Time Use Survey asked members of the public to complete a diary of their activities for a sample time period. This may increase the accuracy of what is actually happening, but it is tedious and requires a substantial commitment from the person completing the record. As with the other approaches that give specific time intervals, the period covered by the diary may not be representative of the person's lifestyle or valued roles and relationships. For example, a diary covering the month of August will probably miss out college attendance. The Citizen Audit takes a simpler route by asking people to say how many hours in a typical weekday they spend on certain activities.
- Third party accounts and observation. In one study (Joyce et al 1989) comparing the results of diary keeping by care staff with simultaneous direct observation, substantial inaccuracies were found in the diaries. This may have been partly due to the fact that the diary also carried an account of staff effectiveness. Similarly, asking informal carers may lead to some distortions.

- Postal questionnaires. This relies on the person's ability to understand what is required and skills to record a written response, their willingness to disclose information, and their cooperation to make time to complete the return. People who do not read are likely to be excluded from this format.
- Interviews. Most interviews are structured or semi-structured and thus can restrict the range of issues discussed or the possible responses. On the other hand, the presence of a person can help with clarifying and interpreting, maintaining interest and drawing out relevant material. However, people who are uncomfortable with strangers or who use unconventional means of communication may find this format difficult.

Who has covered what?

The following tables show surveys and research studies that have covered each aspect of inclusion. The full reference for each study can be found in the bibliography. The tables only include those studies that have been reviewed using the pro-forma shown at Appendix 1.

Demographics

	Sample size	Housing	Income	Education attainment	Age	Ethnicity	Disability
Avon		•	•	•			•
Barber & Hupp	27	•					•
British Household Panel	10,000	•	•	•	•	•	•
Census	All	•		•	•	•	
Citizen Audit	23,000		•	•	•	•	•
Communal Establishment Pilot Survey	707	•	•	•	•		•
CUES		•	•				
Davis	82	•			•	•	•
Dept of Health 'Opinions'	2,000						
General Household Survey Social Capital Module	13,250	•	•		•	•	•
Health Education Monitoring Survey	5,800	•	•	•	•	•	•
Health Survey for England	8,452		•	•	•		
Home Office 'Citizenship'	15,475	•	•		•	•	
Krishna & Shrader							
Narayan			•	•	•	•	
O'Driscoll	670	•			•	•	•
Priebe	55	•	•	•	•	•	•
Psychiatric morbidity	8,900	•		•			•
Rose	2002	•	•	•	•		•
SASS							
Scottish Household Survey		•	•	•	•		•
Sefton							
Survey of Volunteering	1500						
Time Use Survey	11700		•		•		
Webber	300	•	•	•			

Social Roles

	Employment	Education	Volunteering	Exercise	Faith communities	Neighbours	Arts & culture
Avon	•	•	•	•	•		•
Barber & Hupp							
British Household Panel	•	•			•		
Census	•	•	•				
Citizen Audit	•	•		•	•	•	
Communal Establishment Pilot Survey	•					•	
CUES	•	•		•			•
Davis		•	•	•	•	•	
Dept of Health 'Opinions'							
General Household Survey Social Capital Module	•						
Heath Education Monitoring Survey	•	•		•			•
Health Survey for England							
Home Office 'Citizenship'	•	•	•	•	•	•	•
Krishna & Shrader			•				
Narayan	•	•	•	•	•		•
O'Driscoll						•	
Priebe	•	•					
Psychiatric morbidity	•					•	
Rose	•			•	•		•
SASS	•				•		•
Scottish Household Survey	•	•				•	
Sefton			•				
Survey of Volunteering			•				
Time Use Survey	•	•	•	•			•
Webber	•	•	•				

Relationships & Psychological

	Family networks	Social Networks	Friends and acquaintances	Support and contribution	Self esteem	Sense of affiliation	Attitude toward excluded people
Avon	•	•	•				
Barber & Hupp	•	•	•	•		•	
British Household Panel	•				•		
Census	•						
Citizen Audit	•	•	•	•	•	•	•
CUES	•	•	•		•	•	
Davis	•	•	•	•	•	•	
Dept of Health 'Opinions'							•
General Household Survey Social Capital Module	•	•	•	•			
Health Education Monitoring Survey					•	•	
Health Survey for England	•	•	•	•	•	•	
Home Office 'Citizenship'	•	•	•			•	•
Krishna & Shrader							
Narayan	•		•	•	•	•	
O'Driscoll	•	•	•	•	•	•	
Priebe	•	•	•				
Psychiatric morbidity	•						
Rose	•		•	•		•	
SASS	•	•	•			•	
Scottish Household Survey	•	•	•				
Sefton					•	•	•
Time Use Survey							
Webber							

Appendix 1 – Proforma for reviewing surveys and research studies

1. Your name and contact details.
2. The name of the measure.
3. The measure is available from (contact details, publisher, journal or book where the complete measure is to be found)
4. Cost, if sold separately.
5. Guidance on how to use the measure can be found in...
6. Number of people ('subjects') who have provided data.
7. Number of separate studies where the measure has been used, with dates.
8. 'Service users' were involved in... (tick as many as apply)

The research design		Data provision (i.e. as 'subjects')		Data collection (e.g. as interviewers)	
Data analysis		Data interpretation		Dissemination	

Have materials been adapted so that data can be gathered from...

A visually impaired person		A non-reader		A hearing impaired person	
A person who doesn't use words to communicate		A person with limited reading skills		A person with severe learning disability	

9. What is the average time needed to provide data (e.g. how long would it take a 'subject' to complete the questionnaire, on average, or for how long would the person be observed?)

10. Focus of the measure (tick as many as apply)

The person themselves		The host organisation, its staff and arrangements that might support participation		Significant others – people in the background who might influence success	
People with power, such as education, health and social care staff.		The new community – 'non-disabled' co-participants in the setting			

11. Social inclusion themes covered by the measure (tick as many as apply and add any extra you want)

Demographics

a. Housing		b. Income		c. Educational attainment	
d. Age		e. Ethnicity		f. Disability	
g. Other support need					

Social Roles

h. Employment		i. Education		j. Volunteering	
k. Sports and exercise		l. Faith communities		m. Neighbours	
n. Arts and cultural activities					

Relationships

o. Family networks		p. Social networks		q. Friends & acquaintances	
r. Support & contribution					

Psychological

s. Self esteem		t. Sense of affiliation & belonging		u. Attitude towards excluded people	
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Organisations

v. Any action that supports people at risk of exclusion	
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12. What sort of data is gathered? (tick as many as apply)

Written questionnaire		Structured or semi-structured interview		Unstructured interview	
Observation		Diary		Focus group	

13. Data is interpreted with the help of...

Statistical analysis		Formal theme analysis		Impressions	
Other (specify)					

14. Have any of the findings from the measure been compared with other populations? Please explain.

15. The measure has been used with (tick as many as apply)

Children	<input type="checkbox"/>	People with learning difficulties	<input type="checkbox"/>	People with mental health problems	<input type="checkbox"/>
Adults	<input type="checkbox"/>	People with communication difficulties	<input type="checkbox"/>	General populations	<input type="checkbox"/>
Others at risk of exclusion (please explain)					<input type="checkbox"/>

16. Additional comments.

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Continuous annual survey aiming for 40,000 interviews per annum with adults aged 16 and over in England and Wales, including a 3,000 ethnic boost. No actual questionnaire on this website. More from bcinfo.rds@homeoffice.gsi.gov.uk 'Follow up D' has sections on concerns about crime and social cohesion that might uncover attitudes to people with severe mental illness.

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employment characteristics, 3.3.3 on housing tenure, 6.3.3 on overcrowding, 5.2 on measuring incomes, 6.2.3 on leisure and entertainment, 8.2.1 on current activity of non-working lone parents, 8.2.5 education and training, 13.2.2 attitudes towards work, 13.3.1 measures of morale.

Families and Children survey <http://www.dss.gov.uk/asd/asd5/rrep161.html> . Covers employment. 5397 respondents. Para 2.6 is on modelling the move into work of 16+ hours, 3.10.2 is on hours of work.

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General Household Survey

http://www.statistics.gov.uk/ssd/surveys/general_household_survey.asp
Covers social networks. Questions 22 and 23 of GHS 2000/01 are used to form Indicator COM 9 of the Audit Commission set of Social Capital Indicators. Questions 35,26,38,39 are used to form COM 28 and COM 29. Survey has been run almost continuously since 1971, interviewing approximately 13,000 addresses each year. Collects data on all adults aged 16 and over in private households.

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Headline Indicators of Sustainable Development in the UK.

<http://www.sustainable-development.gov.uk/indicators/headline/index.htm> H3 is on employment, H4 on poverty and social exclusion, H5 on education, H6 on health, and H7 on housing.

Health Education Monitoring Survey

http://www.statistics.gov.uk/ssd/surveys/health_education_monitoring_survey.asp 1998 survey of one adult aged 16 or over in 5,800 households in England. Looked at a range of health promotion indicators and social inequality, social capital and health-related behaviours.

Health Survey for England 2000 <http://www.doh.gov.uk/public/hthsurep.htm>.

Overall survey included 8,452 people aged 16 and over in England, of whom 6,840 completed the social capital module. The survey has been repeated annually since 1991 with a standard set of core questions and then each year has varying modules. The module for 2000 was on social capital. The overall survey includes tests of general and mental health by using a questionnaire

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Scale of Attitudes towards Disabled People.

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Scottish Recovery Index – this is the Scottish version of ROPI that has been developed by Simon Bradstreet from the Scottish Recovery Network.

Sefton, T.; Byford, S.; McDaid, D.; Hills, J. & Knapp, M. (?) *Making the most of it: economic evaluation in the social welfare field* York: Joseph Rowntree Foundation. ISBN 1 84263 070 9.

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quality of social integration in the week prior to subjects' attendance at a psychiatric clinic.

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shows that men's volunteering is different to women's.

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Supporting People User Survey currently being designed and the final questionnaire should be ready for use December 2002.

Survey of English Housing.

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Thornicroft, G. & Tansella, M. (1996) *Mental Health Outcome Measures* Heidelberg: Springer Verlag.

Slade, Mike *Threshold Assessment Grid* Institute of Psychiatry.

Stickley, Theo *Evaluating Social Inclusion* measure designed by a group of mental health service users.

Time Use Survey.

http://www.statistics.gov.uk/themes/social_finances/timeusesurvey/default.asp
Sport and culture included, as well as time spent alone. The specific questions are not given in the summary. Data stored at Data-Archive so fee charged for access. 11,700 adults aged 16 or over in households in the United Kingdom provided data via a self-completion diary and a questionnaire.

UK Data Archive. www.data-archive.ac.uk

UK700. This multi-site study of 700 people on the Care Programme Approach receiving mental health services involved Dr Kwame McKenzie. 92% of clients said that they did not work. Of the 59 who said they did work the average working week was 25 hours (range 2-60 hours). Perceived safety is perhaps associated with victimisation, about which there is literature and research. 65% of the UK700 study said that they saw a relative at least once a week. 60% said that they had a close friend that they could confide in (although more likely to be single, people with mental health problems are less likely to move away from home because of work and so are more likely to see relatives. In the UK700 study the average number of moves of towns since coming into contact with mental health services was 1.1. There may be more time to make friendships if you are unemployed. Asking about voluntary work

may reflect the actions of mental health services in pushing people into this activity, rather than the altruism of the person themselves. 32% of the UK700 study had attended church in the last month (ranging from 40% in the Caribbean origin group to 24% in the white group). In the UK700 study 20% had been out and participated in or watched sport.

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Webber, Michael, Resource Generator UK.

Whitaker, P.; Barratt, P.; Potter, M. & Thomas, G. (1998) Children with autism and peer group support: using 'circles of friends' *British Journal of Special Education* 25, 2, 60-64.

WHOQOL – 100. The World Health Organisation Quality of Life instrument is available in two forms. See <http://www.who.int/evidence/assessment-instruments/qol>

Wieland (2006, forthcoming) *The Distal Support Measure* is the first instrument to measure quantitatively the presence of casual community relationships in the lives of participants. The questions included in this instrument were based on the findings of previous qualitative studies (Corin & Lauzon, 1992, Beal, 1999) in which participants reported valuing their routine interactions with other community members at restaurants, retail establishments and other public places. For an identified potential source of distal support to be considered a distal support, three or more positive scores on the 5 questions addressing the participants attitude toward the place (Do you look forward to going there?) and degree of involvement with others at the specified establishment (Do others recognize/acknowledge you when you come in?; Do you know their name(s)?; Do they know your name?; and Do you consider others there to be friends or acquaintances?) had to be affirmed. The total number of distal supports for each participant was summed.

Willer, B. Community Integration Questionnaire, Copyright by OBIA © 1991. Ontario Brain Injury Association. <http://www.tbims.org/combi/ciq/>. *The 15-item Community Integration Questionnaire (CIQ) is used to measure community integration. The CIQ has three subscales to measure home, social and productive functioning based on the frequency of activity and role performance in each domain. The total integration score is the sum of the home, social and productive integration scores.*

Youth Lifestyles Survey. <http://www.homeoffice.gov.uk/rds/pdfs/hors209.pdf>
Focus on crime.