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Structured observational research in services for people with learning disabilities

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School for Social Care Research

Structured observational research in services for people with learning disabilities

Jim Mansell

Methods Review 10

Improving the evidence base for
adult social care practice



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Structured observational research in services for people with learning disabilities

ABSTRACT

This review focuses on structured observational research, primarily in services for people with learning disabilities. Observational research is particularly useful where people using services are unable to answer interviews or questionnaires about their experiences, and where proxy respondents may not be sufficiently accurate sources of data. The review illustrates the use of observational data in assessing and improving the quality of services. Using examples from the research literature, the review deals with the question of what to observe and how to define it so that the information gathered is valid and reliable. It deals with sampling (how often to observe and for how long) in order to obtain representative information, considers the practical steps that have to be taken in order to make observations in services, and shows how to analyse and present observational data.

RECOMMENDATIONS FOR RESEARCH ON ADULT SOCIAL CARE PRACTICE

- Given evidence that measures of process and care standards often do not adequately reflect the lived experience of people using care, researchers should include observation as one of the data collection methods in routine use in social care research.
- Researchers should include quantitative observational data collection where this increases the accuracy of measurement and the ability of the research to discriminate between different outcomes.
- In doing so, they should attend to the definitions and codes used, making sure these address the questions of interest and ensuring that they are properly developed and tested to be valid and reliable in use.
- They should also attend to sampling to ensure sufficiently representative settings, people, situations and times at which to collect observational data.
- In carrying out quantitative observational research, they should pay attention to the same issues of consent, privacy and protection as any other social care researchers.

KEYWORDS

learning disability, observation, time-sampling, behaviour, activity

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INTRODUCTION

Finding out about the experience of people needing social or health care is a fundamental requirement of policymakers and practitioners. Understanding people's experiences permits evaluation of whether the aims of policy are being translated into practice in the way intended, whether there are unintended and unanticipated consequences which need to be addressed and whether there are areas of experience not touched by practice to which attention should be given.

Many people can be asked directly about their experiences through interview or questionnaire. Methods might need to be adjusted so that people understand the questions they are being asked, feel that they are being listened to and understood, and are willing to take part; but with such adjustments people can say what their experiences are. For some people however, this is not possible: no amount of adjustment can enable them to respond to interviews and questionnaires, because of the nature and severity of their cognitive disability. People with learning disabilities or people with dementia, for example, may not be able to respond (or respond fully) to interviews and questionnaires.

In these circumstances a common alternative is to ask someone who knows the individual to respond on their behalf. Responses from proxies have been found to correlate with self-reports in some studies but not in others; higher correlations are achieved when people are asked about objective circumstances rather than about subjective experience (Cummins 2002; Perry and Felce 2002; Stancliffe 2000). However, even here proxy responses can diverge widely from direct observation (Joyce *et al.* 1989). Proxy respondents may not be accurate, perhaps because they do not know what the person experiences or because their own interpretation colours their responses.

Structured observation has been widely used as an alternative to, or in addition to, proxy respondents, where the severity and complexity of people's cognitive impairment prevents them describing their experience using other methods. Observation has the advantage, as a research method, of directly accessing the 'lived experience' of people using services. It is not filtered through the responses of proxies and it is not based on assessments of states or capacities. It involves examining what actually happens. Thus, for example, in the quality of life domain of *personal development* (Schalock *et al.* 2002), a rating scale might indicate that a person has particular life skills, but direct observation can be used to find out whether they are actually using them. In *interpersonal relations*, a person might be recorded as having a certain number of friends, but direct observation can be used to find out whether these friends actually interact with the individual when they meet them. In *emotional wellbeing*, direct observation can show how often and in what circumstances challenging behaviour actually occurs. Observation can, of course, be used as part of a mixed-methods approach in which other approaches are also used to gather information.

Although observational research is particularly useful when working with individuals who are unable to participate in other ways, it can also be an important and useful approach even when individuals are able to be interviewed. For example, people with learning

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disabilities or their staff may be likely to tell researchers what they think they want to hear, and may be reluctant to say things they believe may be considered negative or critical of the service. In some cases people's life experiences may mean they have very low expectations of services, so might indicate that sufficient support is provided and provided well. However, observational data may provide evidence which usefully contradicts this and so highlight weaknesses and limitations of the service, which the people receiving that service may not report.

Direct observation has been used in the evaluation of mental health services (see for example Tyson *et al.* 1995; Whittington and Wykes 1994) and services for older people (Brooker 1995; Brooker *et al.* 1998; Brooker and Surr 2006) but it has been most widely used in studies of services for people with learning disabilities. Reviewing the whole field of observational measurement in adult social care is beyond the scope of this review. The purpose of this review is therefore to describe structured observational methods and applications in learning disability so that researchers in social care and research students learning about methodology can understand how observations can be carried out and how they can be used in evaluation and research.

DIRECT OBSERVATION AS A RESEARCH METHOD

Observational methods have been widely used in qualitative research, including research in learning disabilities. Oswin's seminal study of children with learning disabilities in residential care, *The Empty Hours* (Oswin 1971), used this approach to describe the neglect experienced by children in institutional care at weekends. Owen *et al.* (2007) used over 200 hours of participant observation to describe the move of a group of residents from institutional to community services. Clement and Bigby (2010) used direct observation to understand how group homes for people with learning disabilities worked. Figure 1 gives an example from Mansell *et al.* (2005) drawn from a day in the life of Joan, a woman with severe learning disabilities living in a group home, during and after breakfast.

These kinds of qualitative approaches to observation can provide rich, detailed description, unconstrained by predetermined concepts and categories. They are therefore particularly useful for describing the complexity of what is observed, and for generating hypotheses about it and about relationships between different factors or elements (for example, between the behaviour of staff and those they support). As clearer descriptions and possible explanations emerge, new questions arise. How many people experience this, under what conditions? Does the hypothesised relationship really exist? These questions are best answered with methods which entail quantitative measurement of the observed activities and behaviour.

In quantitative observational studies, the researcher typically spends time in the same situation as the person or persons they are observing, recording what that person does and what happens to them. The researcher tries to minimise their impact on the situation, since their goal is to describe what typically happens for the person or people they are

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Figure 1: Extract from 'A day in the life of Joan' from Mansell *et al.* (2004)

08:30 Joan is sitting at kitchen table with two other clients. She has eaten toast and is drinking tea. A member of staff enters the room and says, 'How are you? Looking very pretty this morning.' One of the clients agrees and repeats these words to Joan.

At 08:33, two members of staff are in the kitchen; Joan starts moaning quietly. Staff leave the room soon afterwards.

08:44 (Nobody has spoken to Joan since 08:30.) Joan starts twiddling a rubber glove and then takes herself to the toilet. Two members of staff are in the office and do not notice this; others are elsewhere in the building.

08:50 Joan walks into the office; her clothes need adjusting. There is one member of staff in the office, who speaks to her. Joan does not respond and starts twiddling the glove. The member of staff leaves.

08:57 The member of staff returns and tries to rouse Joan from the chair on which she is sitting cross-legged, while twiddling the glove. The member of staff is very tentative, and fails to get a response. Another member of staff comes in and helps by guiding Joan off the chair, while asking her, and explaining that she will be late for day centre.

09:00 Joan leaves the house with a member of staff and other residents to meet the day centre bus, which is already waiting (they are late). The journey takes half an hour. During this time, Joan is not spoken to and nor does she attempt to communicate.

observing. They record the person's experience in a structured way. These data can then be presented for individuals or groups, and used to compare different people, situations or services. Observational methods have been used to examine the effect of different arrangements for living and for day-time occupation (different models, buildings, staff ratios), the way staff interact with people with learning disabilities they support (including both the quantity and quality of support), the extent to which people with learning disabilities take part in different activities at home and in the community and the differences between people with different levels and kinds of disability.

This review illustrates the use of observational methods to examine these issues, drawing on the published research evaluating services for people with learning disabilities. It then deals with the methodological issues which arise in using this approach, starting with the question of what to observe and how to define it so that the information gathered is valid and reliable. It deals with sampling (how often to observe and for how long) in order to obtain representative information. It considers the practical steps that have to be taken in order to make observations in services. Using examples from the research literature, it shows how to analyse and present observational data.

ILLUSTRATIONS OF OBSERVATIONAL RESEARCH IN LEARNING DISABILITY SERVICES

Direct observation has perhaps been most widely used in studies of deinstitutionalisation and community living. In their review of British research in this area, Emerson and Hatton (1994) found 28 studies which had used direct observation of resident engagement in meaningful activity to evaluate the quality of residential services (usually in combination with other measures).

As an illustration, one of the earliest examples of the evaluation of supported housing for adults with severe and profound learning disabilities was carried out by Felce *et al.* (1986). They studied the lives of 12 people, six of whom were living in one of the first staffed housing schemes in England (Felce 1988; Felce and Toogood 1988; Mansell *et al.* 1987) and six who were living in institutions but who subsequently moved to housing schemes. Each person was video-recorded for three hours in the period before and during the evening meal on two occasions. The video-tapes were then analysed by observers who recorded each person's activity, the social interaction and contact they had with staff and the occurrence of challenging behaviour. People living in the two houses were engaged in meaningful activity on average for 51% and 56% of the time, compared to an average in the institution of 23%. The main activity in the houses was domestic activity (28% and 30% compared with 7% in the institution). Contact from staff was received for much more time in the houses (17% and 14%) than in the institution (1%). Challenging behaviour, in the form of aggression, was not observed at all in any setting. There were large variations between individuals in the results obtained.

The finding that people with severe and profound learning disabilities spend more time engaged in meaningful activity and receive more contact from staff in supported housing than they do in institutions is common in observational studies, and has been explored in more detail in a number of areas. The effect of the individual needs and characteristics of individuals living in different services has been studied, showing lower levels of engagement in meaningful activity among people with higher support needs (Felce and Perry 1995; Mansell 2006). Time-budget data from studies of the general population suggest that typical engagement levels are over 95% (Szalai 1972).

Different kinds of residential environment have been studied. Emerson *et al.* (1992) found that people with severe and profound intellectual disabilities and serious challenging behaviour living in houses on the edge of a hospital campus were only engaged in meaningful activity for, on average, 14% of an 11-hour day, and that contact from staff was disproportionately given to people with the most serious challenging behaviour. In a larger study of which this was part, Mansell (1994, 1995) showed that people experienced much higher levels of engagement in meaningful activity in well-organised supported housing in the community (31%) compared with either institutions (12%) or special treatment units (15%). A number of studies have suggested that 'second-generation' supported housing has not achieved such good results as the early demonstration projects

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(Bratt and Johnson, 1988; Emerson *et al.* 2000b; Evans *et al.* 1985; Hughes and Mansell, 1990; Joyce, 1988).

Observation has also been used to explore the experience of people with learning disabilities in day centres and in supported employment. Lowe *et al.* (1992) observed activities in two day centres and found average engagement levels of 66% and 50% in within-centre activities and 66% and 77% in activities outside the centre. However, they noted that activities were often shorter than planned, that when activities were not planned engagement levels were much lower and that the engagement of people with highest support needs was much lower than the average and influenced the results for individual activity sessions. Pettipher and Mansell (1993) observed activities for people with different levels of disability in an adult training centre. They found that people with the lowest support needs spent, on average, 66% of their time engaged in meaningful activity; people with moderate support needs spent 46% of their time engaged; and people with the highest support needs spent 22% of their time engaged (equivalent to an hour and six minutes in a notional 5-hour 'working' day). An important reason for people with high support needs not being engaged in meaningful activity was that there was no activity for them to do – they were sitting or waiting for activities to start. Kilsby and Beyer (1996) compared engagement in day centres with that in supported employment for people with low support needs and found significantly higher engagement in employment (81%) compared with the day centres (72%), the same level as among non-disabled workers (Beyer *et al.* 1995).

Observation has also been used in support of inspection. Perry and Felce (2003) studied 154 people living in 47 community-based residential homes as part of a Social Services Inspectorate study. They found average engagement levels of 42%, with no significant differences between statutory, voluntary or private provision and very wide variation between individuals, apparently influenced mainly by residents' need for support. A direct comparison between levels of engagement in meaningful activity measured by observation and inspectors' ratings of care standards (Beadle-Brown *et al.* 2008a) found no relationship between them. The authors suggested that the care standards were primarily focused on processes rather than on the lived experience of people in residential homes and that they should be revised to focus more strongly on outcomes.

Apart from variations in the level of support needed by the people involved, differences in levels of engagement in meaningful activity appear to be primarily the result of staff. In contrast to what might be expected, the staff:resident ratio does not appear to be strongly related to engagement in meaningful activity – services with more staff do not necessarily enable people to participate in more activity (Felce *et al.* 1991; Mansell *et al.* 2008; Mansell *et al.* 1982b). What are important are the care practices of staff, and particularly whether they enable the people they support to take part in activities, using an approach such as 'active support' (Ashman *et al.* 2010; Mansell *et al.* 2005).

Observational studies have shown that staff using active support substantially increase the amount of facilitative assistance they provide, and that this in turn leads to increases in

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engagement in meaningful activity by the people they support (Jones *et al.* 1999; Koritsas *et al.* 2008; Mansell *et al.* 2002; Stancliffe *et al.* 2007; Stancliffe *et al.* 2008b; Totsika *et al.* 2008). Although primarily quantitative in approach, observation has also been used to examine the quality of interactions between staff and residents (Brooker and Surr 2006; Oakes 2000).

Thus, quantitative observation has been used to evaluate service quality and to understand what lies behind variations in quality, in terms of the individual characteristics of people being supported, the kind of service supporting them and the organisation of that support as expressed in the pattern and content of staff-client interaction.

CHOOSING OBSERVATION AS THE APPROPRIATE METHOD

Observation requires more time, and therefore more money, than some other methods of collecting data about services. It should therefore be used where its benefits outweigh the extra costs. The benefits of observation are that it directly measures the experience of people using services. It is therefore useful in situations where people cannot respond to interviews or questionnaires and where the responses of potential proxies are not likely to be sufficiently accurate. In these situations it is likely to continue to have an important place in the range of research methods used in evaluating services.

The main limitation of observation as a research method is that it is more expensive in terms of time, and therefore money, than some other methods. For researchers, it may be possible to reduce the cost by working with organisations that use observation as part of the monitoring of their own service quality. Ashman and Beadle-Brown (2006) described the results of an audit of 138 residential services (registered care homes or supported living services) provided by the charity United Response. Observational data, together with other kinds of information about the quality of life experienced by people being supported and the organisation's processes and resources, were collected by a special team trained by researchers. The same kinds of quality-control procedures were used as in research, and the data were analysed by the researchers. A similar approach was used by Beadle-Brown *et al.* (2008b), where data collection was funded by the charity (the Avenues Trust) as part of its commitment to measuring quality, but observations were carried out by researchers.

Observational research will require ethical approval and researchers will therefore have to address issues of consent, the appropriateness of the method given the focus of the study and so on. People participating in structured observational research may lack capacity and may therefore require the protection of the Mental Capacity Act (MCA) 2005. In principle, these issues are no different from studies using other methods. Ethics committees may need reassurance that observation will not be intrusive and that people will be able to withdraw at any time. Figure 2 gives an example of the approach taken to consent with people with severe and profound learning disabilities by Ashman and Beadle-Brown (2006), prior to the implementation of the MCA.

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Figure 2: Consent procedure from Ashman and Beadle-Brown (2006)

We sought consent from the people we support prior to the observation using an information sheet, which could be read out and/or supplemented with a range of alternative communication techniques. We made time for people we support to raise any questions they may have had about the evaluation, before and after the observation took place.

When an individual's capacity to consent to the observation was uncertain, we used particular tools to help determine people's preferences. If this was still too difficult, we weighed the risks against the benefits.

The final stage of the consent procedure was during the observation itself. For many of the people we support, it was only when they experienced having someone in their house to observe what was happening that they were able to make a real choice. We were therefore clear that consent was not static and could be withdrawn.

People were given the choice about whether or not they took part in the project on an ongoing basis and we were keen to ensure that those people should feel comfortable. If during the observation someone showed signs of being uncomfortable and/or upset by the observer's presence, this was taken as evidence of withdrawal of consent/agreement and the observation stopped immediately.

SELECTING AND DEFINING BEHAVIOUR TO OBSERVE

Most observational studies evaluating services for people with learning disabilities have focused on up to four areas of behaviour: the extent and nature of the person's involvement in constructive activity, the contact they receive from other people, their own communication with others, and the extent and nature of any challenging behaviour they show.

Felce *et al.* (1980a), in their study comparing large long-stay hospitals for people with learning disabilities with smaller community-based units, used a simple binary classification of resident activity as either 'engaged' in meaningful activity or 'disengaged'. Engagement included both using materials and objects and social interaction; disengagement included both doing nothing and challenging behaviour. Depending on the nature of the questions being answered, these broad categories have been broken down in later studies. For example, Felce and Perry (1995) broke down the 'engagement' category to distinguish non-social activity (like leisure, self-care or housework) from social interaction with other people, recognising that social activity might be influenced by, for example, the degree of learning disability of the people being observed or the number of staff supporting them. Similarly, Mansell (1994) distinguished using equipment (for

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example operating a food blender, hedge trimmer, vacuum cleaner) from simpler practical tasks like sweeping up, laying a table or folding laundry to find out whether people were being supported to take part in more complex activities. Hatton *et al.* (1995) distinguished between two types of disengagement: where the person was doing nothing, and where the person was undertaking activities that were non-functional and/or age-inappropriate.

Similarly, many studies have examined how much contact from staff or others is received. For example, Porterfield *et al.* (1980) distinguished positive contact (for example, praise, affection) from negative contact (such as reprimanding or preventing someone from doing something) or neutral contact (for example, conversation). Studies which have focused on the kind of support from staff likely to promote successful engagement in meaningful activity by people with severe and profound learning disabilities have distinguished assistance (facilitating or supporting someone) from other contact (for example Emerson *et al.* 2000b; Felce *et al.* 2000b; Felce *et al.* 2002a; Jones *et al.* 1999). Some studies have distinguished whether contact is received from staff or members of the public. Saxby *et al.* (1986) studied the extent to which people with severe and profound learning disabilities were passively accompanying staff in using shops and community facilities or meaningfully participating in the activities involved. They found that contact with members of the household on the trip averaged 6% of the time, whereas contact with members of the public averaged 2%. Mansell (1995) distinguished whether contact in residential settings for people with severe and profound learning disabilities and serious challenging behaviour was received from staff or from other people with learning disabilities in the same setting and found negligible amounts of contact from other residents, reflecting their degree of learning disability.

Communication or social behaviour by people with learning disabilities has also been studied. For example, Mansell (1994) distinguished clear social acts (e.g. speaking to someone, tugging their sleeve) from unclear social acts (e.g. vocalising and waving arms near a person). This study also coded social acts to the person observing in order to check whether the presence of an observer prompted residents to interact with them. It found that, with this group of adults with severe and profound learning disabilities and very severe challenging behaviour, negligible levels of social contact from participants to observers were recorded.

Observation of challenging behaviour typically uses a set of codes defining the different types of behaviour which might be observed: self-stimulation, self-injury, aggression, damage to property and so on (for example Felce *et al.* 1998). In addition, specific codes for idiosyncratic behaviours might be used (for example Mansell 1994). Much challenging behaviour is in fact rarely observed, and service evaluations usually collapse the data collected to distinguish self-stimulatory behaviours (such as twiddling laces or rocking) from more disruptive problems like aggression or destruction of property.

All of these distinctions include judgements (including value judgements) about what is important to study. In deciding on the behaviour to be observed and how to define and

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classify it, researchers therefore have to work out and justify their decisions. What is observed and how it is defined depends on the purpose of the study (Bijou *et al.* 1968). If the study focuses on behaviour which has been studied by others, then it may make sense to use definitions and methods which are consistent with them so that the results can be compared. If new measures are developed, these have to be tested and refined, to make sure that they are valid (they measure what it is intended to measure) and reliable (different people using the same measure record the same things).

HOW OFTEN TO OBSERVE AND FOR HOW LONG

Observational studies of services for people with learning disabilities have included studies of the whole waking day, where the purpose has been to compare the overall effect of one type of service against another (Emerson *et al.* 2000b; Felce *et al.* 1980a; Felce *et al.* 1980b; Hatton *et al.* 1995; Mansell 1994, 1995); special activity periods of an hour or so, where the purpose has been to compare different staff support arrangements (Coles and Blunden 1979; Mansell *et al.* 1982a; Porterfield *et al.* 1980); and shorter periods such as that before and during the evening meal, selected because household activities are more likely to occur then (Jones *et al.* 2001a; Jones *et al.* 2001b; Jones *et al.* 1999; Mansell *et al.* 2008; Stancliffe *et al.* 2007). There is some evidence that the early evening period used in this third group of studies can provide an accurate estimate of the pattern of the whole day if a sufficiently frequent observation interval is used (Mansell and Beadle-Brown 2011), although this needs confirmation through further research.

In each case, researchers need to make arrangements to exclude sessions which are not typical; for example, because people are unwell, or some special activity is happening, if more staff than usual have been brought in, and so on.

As well as deciding on the times to sample, observers need to decide how many people should be included in the study. In general, this has not been addressed by researchers, who have included whichever people are in particular settings (for example in a few group homes or a day centre) without addressing the representativeness of those settings. Instead, they report their results with caveats about the generalisability of the findings.

Within each session, observers need a strategy for ensuring that every participant is included. Where the individual is on his or her own, or where only one person in a particular setting is the focus of study, then the observer can concentrate on them throughout. Where there is a group of participants the usual strategy is to spend a period with one person before moving on to the next and so including everyone in rotation. For example, Felce and Perry (1995) observed each person for ten minutes before moving on to the next in a predetermined random order; Mansell *et al.* (2008) observed each person for five minutes. These periods were determined entirely by the practicalities of deploying observers rather than by evidence that the resulting sample is representative of the whole period (see Suen and Ary 1989 for a discussion of scheduling sessions).

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Researchers also need to decide how to record the behaviour of the people they are observing. Two approaches have been widely used: continuous observation and momentary time-sampling. Other approaches, such as partial-interval and whole-interval sampling, do not yield representative results and should not be used (see Suen and Ary 1989) if the aim is to measure the amount of time spent in activity.

Continuous observation requires the observer to record the start and end time of the range of behaviour under study. This is usually done with a handheld computer programmed specifically for the task (Emerson *et al.* 2000a).

The advantage of continuous observation is that it preserves information about how often each behaviour occurs, how long each event lasts and how different behaviours relate to each other in time. Its disadvantage is that it requires close attention and alertness by observers to keep track of the start and end of every behaviour they are recording, and therefore has implications for training and for session length.

Contingency data was used by Felce *et al.* (2000a) to show that the likelihood of engagement in meaningful activity occurring given assistance from staff increased after training in 'active support'; a similar approach was taken by Stancliffe *et al.* (2008a). Hall and Oliver (1992) showed that members of staff were more likely to respond to a person's self-injurious behaviour if this occurred in bouts of longer than ten seconds. Emerson *et al.* (1996) illustrated the use of sequential analysis (where the relationship may not be immediately contingent; see Bakeman and Gottman (1986)) in understanding the causes of challenging behaviour. However, most evaluation studies that have used continuous observation have not used the frequency and contingency data, presenting only average length of time spent in different activities.

The other approach which has been used is momentary time-sampling, where the observer records what is happening at the moment of observation at a predetermined interval (for example every 20 seconds, every minute, or every five minutes). The rest of the time the observer pays attention to what is happening so that they can correctly interpret the behaviour they see at the moment of observation, and they may record notes to aid interpretation of the quantitative data, or other measures (such as the number of staff and residents in the room). Momentary time-sampling can be recorded on paper (including using machine-readable forms), or using a specially-programmed handheld computer (Beasley *et al.* 1993; Emerson *et al.* 2000as; Repp *et al.* 1989).

Momentary time-sampling only provides information about how much time people spend in different activities. It does not provide frequency or contingency data.

The frequency of momentary time-sampling has implications for the representativeness of the data and has been quite widely studied (Klesges *et al.* 1985; Mansell 1985; Powell *et al.* 1977; Repp *et al.* 1976; Saudargas and Zanolli 1990). Liberman *et al.* (1974) reported that there was no significant difference in the percentage of behaviours recorded in four half-hour observation periods compared with ten periods per day and, in a later study

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with the same instrument, Alevizos *et al.* (1978) reported that two observations a day reflected resident activity with sufficient accuracy in a psychiatric hospital with 'characteristically low levels of activity'. Mansell (1985) showed that it was necessary to average a 5-minute momentary time-sample over eight hours to obtain reasonably accurate estimates of behaviours occurring for more than 25% of the time. However, most recent studies have used more frequent time-samples, typically of between 20 seconds and one minute, which would be expected to yield sufficiently accurate estimates over much shorter time periods. In practical terms, if the observer has to be present continuously in the situation they are observing then a frequent schedule is easy to fulfil while still leaving time to make notes or collect other information.

TRAINING OBSERVERS

Once a set of definitions has been developed that reflects the research question, observers have to be recruited and trained and the data collected. Training is focused on accuracy and reliability. Observers need to practice under supervision to make sure that they are accurately coding the behaviour according to the definitions developed. They also need to compare their observations with those made by others to ensure that everyone is recording in the same way. Training can be carried out using video recordings or in similar settings to those where the observations are to be made and continues until an acceptable criterion is reached. If the study lasts for some time, periodic retraining will be required to make sure that observers are still using the definitions correctly. For example, in a study of specialised group homes for people with severe and profound intellectual disabilities and serious challenging behaviour lasting several years, Mansell (1994) reported:

Before each datapoint, observers retrained on the measure by jointly rating video tapes until they reached a criterion of at least 80% agreement. At every datapoint, interobserver agreement was assessed for each participant by having a second observer independently collect data for 30 min (on a few occasions these reliability sessions were missed due to practical difficulties). This yielded 7,615 paired observations (3.6% of the total). During the study, point-by-point agreement was calculated at each datapoint and ranged between 84% and 95% (pp. 378).

Inter-observer agreement, or inter-rater reliability, needs to be calculated based on data collected throughout the study so that all observers are included. Two observers independently observe and record for a period and then their observations are compared to estimate the level of agreement between them. Conventionally, duplicated observations for 20% of the total are often recommended (Cooper *et al.* 2007), though in larger-scale studies a lower proportion may be achieved.

Inter-observer agreement is often calculated as the percentage of pairs of observations in which both observers agree. This is simple to calculate and gives a readily understandable

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index of agreement. This statistic is, however, influenced by the amount of the behaviour observed. For example, if in a 60-minute session using a one-minute momentary time-sample the person is only observed to be receiving contact from staff on two occasions by the main observer and on one of the same and one different occasion by the second observer, they will agree on 58 pairs of observations (97%) even though they only agree on one of the two occasions when contact was recorded. One approach in these circumstances is to calculate occurrence and non-occurrence agreement separately: in this example occurrence agreement is one out of three pairs of observations (33%); non-occurrence agreement is 57 out of 60 (97%). A second approach is to use Cohen's kappa, a statistic which takes account of chance levels of agreement and which ranges from 0 to 1. In this example, kappa is 0.48. A value of 0.6 is conventionally regarded as acceptable (Suen and Ary 1989).

For continuously recorded data, variations of these approaches are used, typically allowing a few seconds leeway between observers' records of onset and offset times (see for example Emerson *et al.* 2001; Stancliffe *et al.* 2007).

OBSERVATIONAL PROCEDURE

Reactivity

A common concern expressed about the use of direct observation as a research method is that the presence of observers will itself change the behaviour of people being observed in a way which influences the subject of the study. This is sometimes called the Hawthorne effect, after an early experiment to increase workers' productivity in an American factory (see Parsons 1974).

Reactivity to the presence of observers is an obvious possibility. People are likely to notice visitors and to take an interest in them. Even if the people with learning disabilities involved are not much influenced, members of staff are likely to be. For example, Bible and Sneed (1976) observed staff work with residents in an American learning disability institution during a visit by an accreditation team. They found a 277% increase in the number of programmed activities completed with residents during the visit, with an immediate reversal to the original level once the accreditation team had gone.

Observational researchers typically use several approaches to deal with reactivity. First, as far as possible, they avoid interfering in the situation. They have to balance the need to be polite and respectful, while not becoming so engrossed in the social niceties that they become a participant in the situation. Thus, they may make a clear distinction between being sociable at the beginning and end of observation periods and focusing on their work during those periods, politely declining opportunities to talk or join in activities going on. This helps other people discriminate when it is appropriate to attempt to involve observers and when not. Figure 3 illustrates the kind of practical guidance given to observers.

Figure 3: Procedure for observers given by Beasley *et al.* (1993)

1. On arrival make sure the living unit staff know who you are and why you are there and tell them that, while observing, you will not usually be able to interact with service users or with them. Allow sufficient time for this before the start of the observation session, especially on the first day of observation for each new client.
2. The aim is to observe as unobtrusively as possible. Although a single observer will often take observations relatively furtively it is important that the observer is placed where they can see everything that could affect the code (e.g. if looking through a window at a client in the garden, the observer must be able to see whether, if the client speaks to another person, that person is reciprocating).
3. Generally, the observer should walk into the room to a position where they can observe the client, avoid eye contact with anyone, stand as still as possible and look at the display until it is time to observe. They should not talk to or distract anyone.
4. Wear flat, soft-soled shoes that will not sound loud on stairs or hard floors. Close doors carefully – some doors with automatic closers may shut with a loud slam. Do not handle materials, move objects or otherwise intervene in the environment unless someone's safety is directly threatened.
5. Do not go into rooms where a person might reasonably be expected to be asleep in bed, undressed, or working with a member of staff on a programme which might be disrupted by another person coming in. Generally, this means not entering toilets or bathrooms, or bedrooms at the beginning and end of the day. The observer should enter these rooms if, for example, the person is doing housework.
6. In order to help clients and staff discriminate when they can talk to observers, make it clear at the outset of the session and put the records away when you have finished. If the observer has been talking to clients or staff before the start of the session, they should make it clear to everyone that they are going to start observing. Further contacts should then be ignored (extinction of client and staff initiating to observers will be helped if the observers avoid eye contact as far as possible). At the end of the session (when no more observations are being taken) put away the records, tell everyone that observations are finished and spend a few minutes socialising.
7. If the person you are observing (or anyone else in view) seems likely to come to serious harm unless you intervene immediately, do so. You can either re-start observations later or go another day if need be.

(continued)

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Figure 3: (continued)

8. Observing in the community may cause more difficulties in terms of protecting the client's privacy. However, it is important to observe in as many situations as possible to get a more accurate picture of a person's level of engagement. This might include Public Houses, restaurants, shops, dentists, doctors, library, public transport and so on. Obviously there are some situations when it would not be appropriate to observe, e.g. in public lavatories.
9. When in the community the decision of when to observe and when not to observe to a great extent depends on observer discretion. Observers should be provided with copies of a brief explanation of the purpose of the investigation (with a contact address on it) which can be given to people, for example a store manager, who may approach them during observation in the community. If at this point the person expresses their unhappiness with the situation then the observer may choose to stop until the client has left that setting.
10. The data collected in this study are important and will influence the lives of many of the people observed as well as other service users in future. The general rule, therefore, is to observe rather than not observe. Confident, unobtrusive observers will rapidly blend in to the background and need not be a critical imposition in the lives of the people observed.

Second, observers try to minimise their influence on the situation by avoiding giving feedback, so that people are not inadvertently coached to behave in ways they think are desirable (in the Hawthorne experiments, it was not just the presence of researchers but the fact that they gave people feedback and that there were financial incentives for better performance that changed what people did (see Parsons 1974)).

Third, researchers notice and record obvious reactions to their presence. This might be done by recording every instance. For example, Mansell (1994) recorded attempts to communicate with observers by people with severe and profound learning disabilities and serious challenging behaviour participating in a study of transfer from institutions to community services, and found that:

Negligible levels of social contact from participants to observers were recorded. Twelve of the 13 participants were recorded as contacting observers for less than 1% of observations. [One person] was recorded as contacting the observer for between 0.1% and 2.25% of observations (average, 0.54%, equivalent to 3.5 min in the 11-hour day observed) (pp. 378).

Even where recording every instance of a reaction to the observer is not part of the measure, researchers can note what has happened and report it. In another report from

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the same study, McGill and Mansell (1995) reported on an individual (Howard) whose engagement in meaningful activity did not increase on moving to a group home:

Howard's level of participation in meaningful activity fell slightly and challenging behaviour (mainly self-stimulation) more than doubled. At the following observation point participation increased and self-stimulation fell, but the observer reported that the participation was very simple manipulation of a guitar prompted by staff, which the observer felt might have been intended to affect the results of the study (pp. 191).

Fourth, observers deal with reactivity by spending enough time taking observations for people to get used to them and for any initial effects of their presence to subside. For example, Mansell *et al.* (1984) carried out pilot observations for 12 days prior to their study, during which time residents and staff had almost completely stopped responding to them during observation periods. Observing for hours at a time, on different days, also makes it less likely that any special effects will be maintained. Supporting people with severe and profound learning disabilities well is a skilled task requiring fluent, practised performance based on a warm and positive relationship between members of staff and the person they are supporting. It may be possible to put up a pretence of this for a short while but it is unlikely to be possible for long.

The final point about reactivity is that even if it occurs it may not prevent useful information being obtained. Studies of care practices show that residents in supported housing receive direct, facilitative assistance from staff (of the kind known to promote engagement in meaningful activity) for a very small proportion of the time – typically well under 10%, or less than six minutes in every hour (Felce *et al.* 2002b; Felce and Perry 1995; Hatton *et al.* 1995; Jones *et al.* 1999; Jones *et al.* 2001a). If this is what is achieved when people are trying to perform as well as they possibly can to influence the observations (so that at other times the level of assistance they provide is even lower), then it still shows that people are not getting the support they need to take part to a fuller extent in the activities of their daily lives.

Abuse or neglect

In addition to advice about the way they should observe, researchers need to know what to do if they observe neglect or abuse or if this is disclosed to them during their visit. There is no difference between observational methods and other approaches in the need for researchers to understand what they should do in these situations. Observers may see poor practice or neglect that seems to be routine, such as people being left unnoticed in soiled clothing, or attempts at communication consistently overlooked or ignored. If they intervene to draw the attention of staff to these practices they will influence the way staff behave towards them and the people they support and they may thereby subvert the purpose of the study. They may also inadvertently lead to individual staff being blamed and punished for what is really a failure of management. In these circumstances feedback in more general terms may be most useful:

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If it does not seem an emergency situation, ie you do not have reason to suspect that anyone is in imminent danger, discuss what has happened as soon as possible with your supervisor (or any senior member of the academic staff if your supervisor is not available). Together you may decide that what you have observed is unpleasant or wrong, but not so serious that immediate action is required, and that the best course of action may be to tackle it with the member of staff at your next visit or make reference to it (perhaps anonymously or in general terms) in the report which goes to managers. Although this may appear to be over-looking poor practice, it is often better to adopt a more strategic, long term view which recognises the extent to which poor practice is built in to services and this may ultimately be more effective in improving poor practice. At this stage you and your supervisor should decide whether, and how, to inform any independent advocate or close relative who is involved with the person (McCarthy 1998, pp. 3).

This advice was written before adult safeguarding policies were generally adopted and these too now need to be considered, particularly in relation to codes of practice that may apply to members of the research team. At the other extreme, observers may witness instances of people at risk of being hurt where they should intervene immediately to protect people from harm:

If people are in immediate and serious danger for whatever reason you should try to assist if you can. For example, if you are left alone in a room with a group of service users and one person attacks another you may need to stop recording and call staff (McCarthy 1998, pp. 2).

Guidance will therefore need to cover a wide range of possibilities and will involve (i) preparation before the study with the organisations and individuals involved (which may be an explicit requirement of ethics permissions), (ii) regular opportunities for debriefing of observers and discussion of any concerns they have, (iii) sharing responsibility for decision-making with more senior and experienced people in the research team, and (iv) providing feedback to service managers, where appropriate in an anonymous form, and/or to people using services or their representatives, and/or to commissioners, regulators and inspectors.

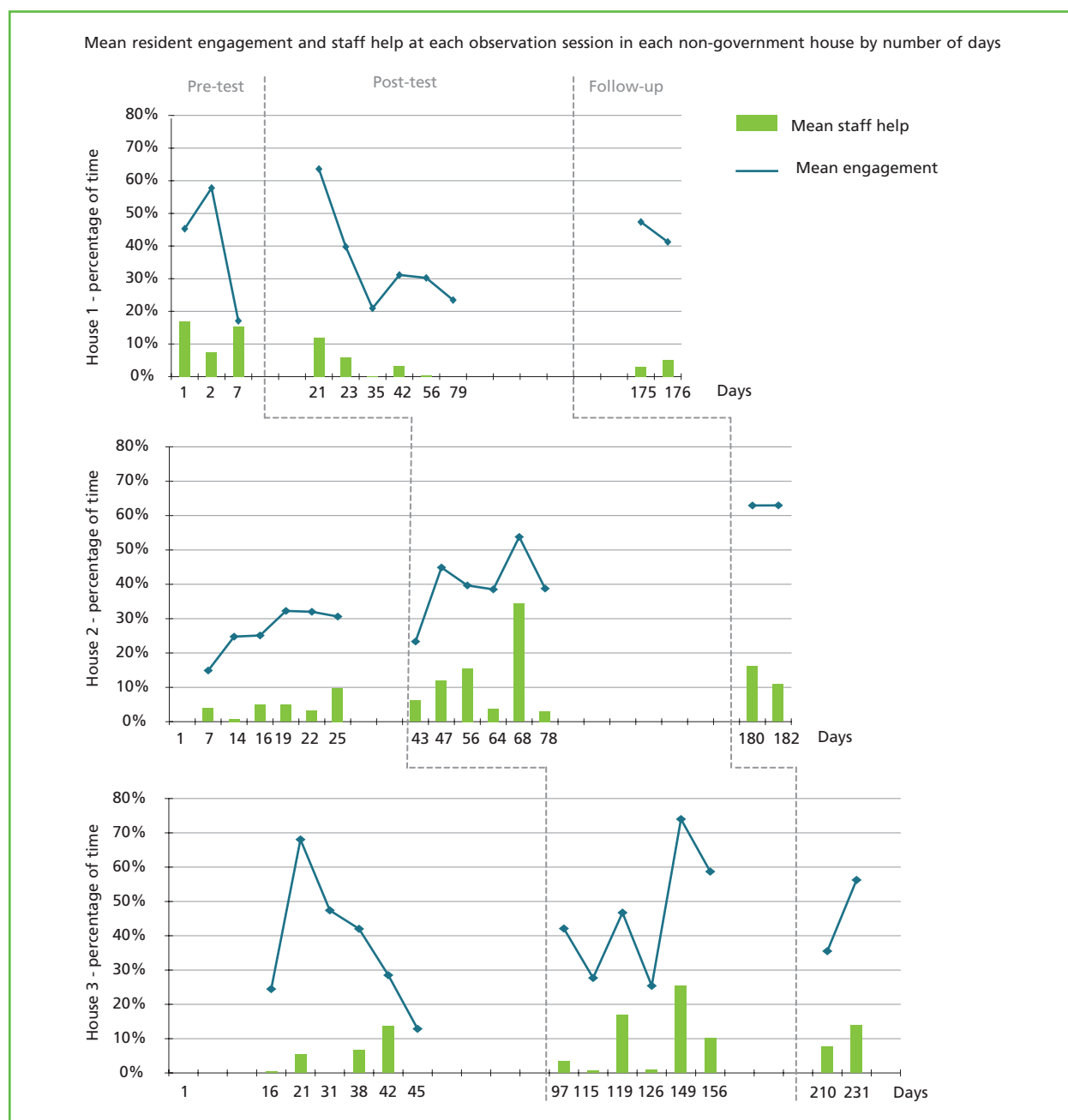
ANALYSIS AND PRESENTATION

As already noted, observational data in evaluative studies are usually summarised as the percentage of time observed that different categories of behaviour or activity occurred. Observational data are most commonly used to compare one situation with another, and are therefore usually averaged across individuals and across observations. For example, Stancliffe *et al.* (2007) presented data on the level of engagement in meaningful activity and the amount of help received from staff for 22 people with learning disabilities living in five houses over 11 to 14 occasions, by averaging the data across observations within the same session and across individuals to give a single average score for each house at

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each session (Figure 4 shows the results for three houses as an illustration). Using a multiple-baseline design, they showed that average scores increased after the introduction of active support in four of the five houses and were maintained at follow-up. This approach has also been used, for example, by Jones *et al.* (1999). The same approach has also been used where the focus of the study is individuals rather than groups (Bradshaw *et al.* 2004; Mansell 1994) and where the comparison is between experimental and control groups (for example Mansell *et al.* 2008).

Figure 4: Example of presentation of observational data from Stancliffe *et al.* (2007)



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Figure 5: Example of presentation of observational data from Mansell and Beasley (1993)

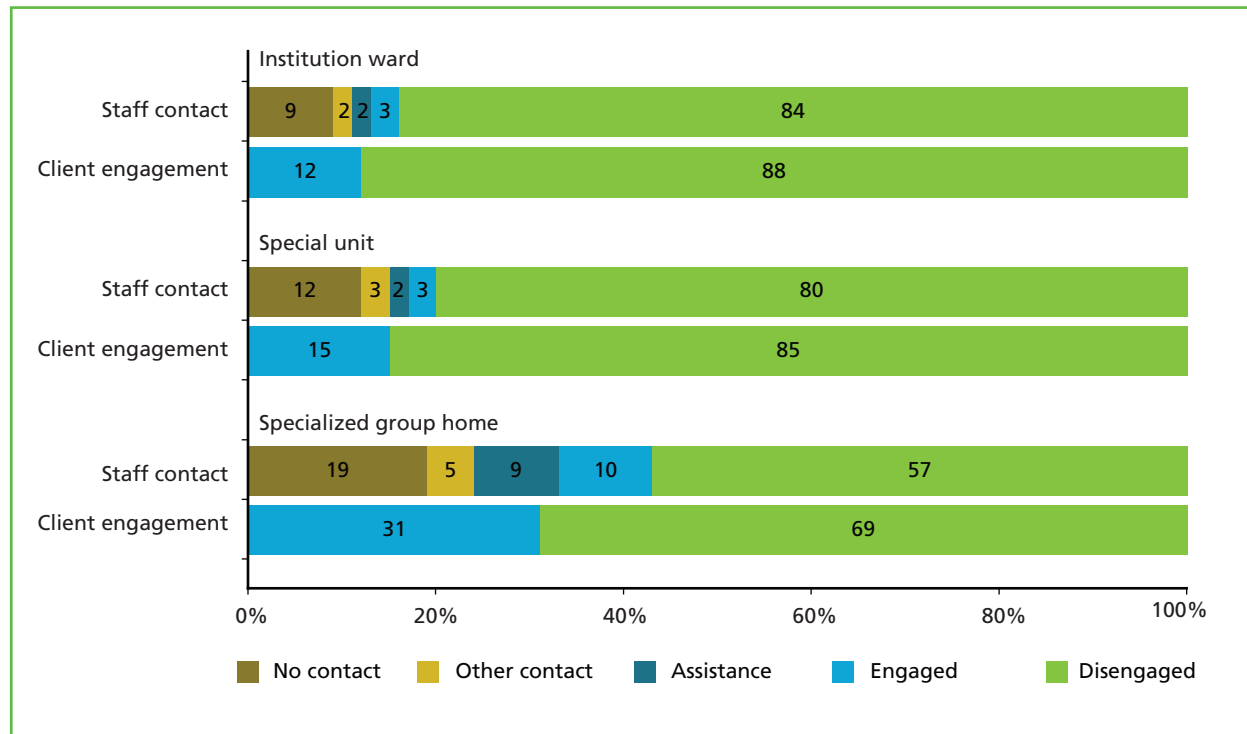


Where continuous data or a frequent time-sample have been taken over a longer period, it is also possible to examine the pattern of activity. For example, Mansell and Beasley (1993) averaged a 20-second momentary time-sample in ten-minute blocks taken over the whole day to compare the pattern of one person’s day while they lived in an institution and after they moved to staffed housing in the community (Figure 5). In the institution, there was a small amount of help in the early morning, and sporadic contact of other kinds from staff through the day. Activity levels tended to peak on only three occasions (breakfast, lunch, and tea). In the house, interesting activities were far more likely to be spread throughout the day, with much higher levels of contact and assistance from staff to enable the individual to take part.

Examples have already been given of the use of continuous data to explore the contingent relationships between events (Emerson *et al.* 1996; Felce *et al.* 2000a; Hall and

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Figure 6: Example of presentation of observational data from Mansell (1995)



Oliver 1992; Stancliffe *et al.* 2008a). Where momentary time-sampled data are available they can also be used to explore the relationship between concurrent events. For example, Mansell (1995) summarised data to show the relationship between receipt of contact and assistance from staff and whether people with severe and profound learning disabilities engaged in meaningful activity (Figure 6). This showed that the extra assistance received by people in group homes compared with institutions was mainly provided when people were engaged in activity, but that the increase in meaningful activity was not all accompanied by assistance – the help provided by staff enabled the people in the study to do more for themselves.

CONCLUSION

The strength of quantitative direct observation is that it measures aspects of the lives of people as they live them, in situations where people using services are unable to answer interviews or questionnaires about their experience, and where proxy respondents may not be sufficiently accurate sources of data. Observational research has been used to provide evidence of a better life in community-based services for people with learning disabilities. It has also shown that the benefits of new service models have not been experienced to the same extent by everyone and that it cannot be assumed that new models automatically provide a better life for the people they serve. It has focused

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attention on how staff provide help to the people they support as a more important predictor than many aspects of the structure and processes of services.

The value of direct observation in understanding how people using care services are supported is evident not only from its use in research, but also from the use of undercover filming by television journalists to document abuse and neglect. No other method provides such direct evidence of the reality of people's lives in situations where they cannot speak for themselves. Observation is therefore likely to continue to be an important addition to the range of methods used in social care research.

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