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**Quality of Life for Adults with Learning Disabilities in Private Residential Care:
Monitoring Aspects of Life Experiences Over Time**

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Abstract

The Quality of Life (QoL) of a sample of 56 adults with Learning Disabilities was studied longitudinally over 18 months while they lived in community-based private residential homes. Six homes participated in the study. The Life Experiences Checklist (L.E.C) Ager, 1990, 1998), which considers a person's home environment, leisure, freedom, relationships and opportunities, was used as a measure of QoL. The L.E.C was administered to participants on three occasions at approximately six-monthly intervals. Simple feedback reports giving overall results for the L.E.C (and other measures) were produced for each home at the end of each of these three phases.

The L.E.C. results showed that overall participants' QoL changed significantly over the course of the study, with assessed QoL peaking at phase two after homes had received the first feedback report, and decreasing to near phase one levels by the end of the study. People living in one of the homes, however, sustained the observed improvement in QoL over time. Comparisons were drawn between the L.E.C results for the sample and the general population living in the same area. The sample experienced a lower QoL than the general population regarding Relationships, Opportunities and Freedom L.E.C. sub-scales and had a comparable QoL regarding the Home sub-scale, and higher scores with respect to the Leisure sub-scale.

Results are discussed in terms of subjective and objective QoL measurement as an indicator of quality of service provision and in particular the effects of feedback and monitoring per se. It is apparent that in the absence of intervention no sustained improvements in QoL are seen in this sample.

Keywords: Quality of Life, The Life Experiences Checklist, Monitoring, Feedback

Introduction

A recent House of Common's Joint Committee (March 2008) has remarked on the slow progress since the publication of 'Valuing People' (Department of Health, 2001) and the gap between policy implementation and actual experience of service users with Learning Disabilities. Though the emphasis is now on a 'Human Rights' model, there is still much evidence of a lack of choice as to where people live and who they live with. This is particularly salient as nine out of 10 homes are in either the private or voluntary sectors. The March 2008 report also states that there is a significant gap in the protection of vulnerable people receiving support in the private sector.

It is now more important than ever that Quality of Life is monitored for people with Learning Disabilities in the private or independent care sector. Monitoring the quality of care is seen as an important task in the improvement of services for people with Learning Disabilities (Hoyes, 1987; Cummins, 2005), yet little is

known of the effects of such monitoring and feedback on the actual performance of community services. This study sets out to explore these issues regarding adults with Learning Disabilities living in private sector residential homes.

Conceptual Issues in Quality Monitoring

If quality monitoring is to have a positive impact on services, three related issues must be resolved. Firstly, appropriate measures of quality must be identified. The quality of life (QoL) of service users has increasingly been viewed as a construct which, while complex, is also susceptible to measurement and summation and can therefore enable cross-service comparisons to be made (Cummins, 2002; Felce, 1997; Felce and Perry, 1995). Although some have argued for the importance of considering both subjective and objective measures of QoL (Cummins, 1997, 2005; and Felce & Perry, 1995), McVilly and Rawlinson (1998) and Hatton (1998) have argued that the finding of long-term consistency in subjectively assessed QoL may make objective measures more appropriate in judging quality of services. Hensel (2001), citing Hatton (1998), argues in her review that the QoL concept, and particularly the measurement of satisfaction as a subjective correlate of QoL, should be abandoned.

Cummins (1993, 1997, 1999, 2001, 2002, 2005), however, proposes as an argument for the 'integrity' of subjective QoL, a homeostatic regulatory model. He proposes that when differing QoL scales are examined, subjective life quality may be expressed as a common statistic, a 'percentage of scale maximum', (%SM). Though Ager and Hatton (1999) argue that subjective QoL within a reasonable range is impervious to objective/environmental changes, Cummins (2002) argues that the fact that subjective QoL is predictable and stable enhances its usefulness as a tool for assessing service delivery. Cummins (2002) further highlights the strong correlation of subjective QoL with related psychological constructs such as self-esteem and optimism and the importance in studies of respondents' satisfaction with 'family and friends'.

The second important consideration concerns the interpretation of measures and the frame of reference used in evaluating the meaning of obtained results within QoL and service delivery contexts. The philosophy of Normalization (Wolfensberger, 1983) suggests that patterns of life which are normative or valued within the wider community, provide the most appropriate reference point in assessing the QoL of individuals with Learning Disabilities.

The Life Experiences Checklist (LEC) (Ager et al. 1988, 1990, 1998), applied in this study is a brief measure of QoL which offers some advantages with respect to these issues. The L.E.C assesses QoL in five domains: the Home environment, Leisure, Relationships, Freedom and Opportunities. Normative data (Ager et al. 1988; Ager, 2008) enables the LEC results for people with Learning Disabilities to be compared. This gives the measure some validity as a measure of objective QoL and provides a useful tool for measuring service delivery. Cummins (2002) argues that because the LEC does not measure subjective features such as 'well-being' (as his scale the Comquol does), that the LEC is not a complete and valid measure of QoL. Where the aim is to evaluate changes in QoL, resulting from incremental improvements in service quality, however, Cummins' (2001, 2005) arguments would suggest that a primarily 'objective' measure such as the LEC would probably be a more sensitive measure than one addressing subjective features of QoL.

The LEC exhibits good test-retest reliability, and shows validity against objective indices of community involvement; it is also sensitive to differences between environments (see Cummins, 2001, for a review). Ager (1990, 1998) has summarised the results of a number of studies which indicate acceptable levels of test-retest scale reliability (0.93 for scale total score, and ranging from 0.91 for Opportunities to 0.96 for the Relationships for sub-scales). Inter-rater reliability is high at between 0.80 and 0.96, and Murphy, Estien and Claire (1996) noted 96% agreement in inter-rater reliability. Validity data (Ager et al 1998) shows that the total scale score correlates negatively with the number of people in a ward and positively with staff client ratios.

A third question in monitoring of QoL is how to use monitoring to improve the quality of services. In this study, homeowners and managers were provided with three simple feedback reports with possible suggestions for improvement at the end of each six-monthly data collection intervals over an 18-month period.

Methodological Issues in Monitoring QoL

Since, for many people with more severe Learning Disabilities, the questions on QoL measures will be answered on their behalf by carers or other proxy respondents, further issues regarding validity and reliability of findings are the use of proxy respondents and response bias (Hensel, 2001). Further issues include the expectations the interviewer brings to the interview (Rapley & Antaki, 1996; Rapley & Ridgway, 1998) and how the interview is orientated and conducted.

Regarding the validity of proxy responses, particularly regarding subjective areas of QoL, the present author agrees that a high level of agreement is required for this strategy to be 'defensible' (Hatton and Ager, 2002). Previous research has, however, at times, shown that objective life quality shows high levels of client-proxy agreement (Perry, Felce & Lowe, 2000). In McVilly and Rawlinson's (1998) review, complexity and salience of the aspect of QoL assessed, affected level of agreement, which has an obvious bearing on instruments used. The level of subjectivity required was found, not surprisingly, to negatively affect proxy-client agreement.

Regarding the interview situation, and the often reported finding of acquiescence in those with Learning Disabilities, Rapley and Antaki (1996) propose the concept of 'acquiescence' in this population as both conceptually cloudy and empirically unproven. Rapley and Antaki (1996) say that inconsistency is often confounded with acquiescence. They further explored the power difference between interviewer and those with Learning Disabilities and what is revealed through resultant conversational analysis as 'shepherding' where interviewers reformulate and re-ask questions and echo back answers.

The Implications of Conceptual and Methodological Issues for the Current Study

One goal of the present study was to look for incremental changes in QoL. It is clear from the literature above that for such a purpose a measure focussing on objective indicators of QoL will be more sensitive. This, together with its relative brevity and the fact that general population norms were available, led

to the decision to choose the LEC as the measure of QoL to be used. The LEC focuses on such objective indicators. Proxy responses from care staff were accepted in the current study (1:4 of the sample) where the person with a Learning Disability was unable to answer the questions.

Method

Participants

Six private sector homes participated in the study. The participating homes were selected from nine homes from a quality monitoring programme which was subject to ethical approval through the regional medical ethics and University ethics panels. Home managers were approached for consent; and each resident approached for consent, relatives were approached if 'informed consent' could not be obtained directly from participants, homes and participants could withdraw from the study at any point and individual home and participant anonymity was assured.

The 56 consistent participants' ages ranged from 18 to 75 years; 26 were female and 30 male. Homes A and B were urban, C and E suburban and D and F rural by location. In terms of self representation and advocacy (see Table 1, for selected characteristics), home A had 12 out of 17 self advocates, B had 8/13 self advocates, C had 7/9 self advocates, D, 5/7 self advocates and homes E and F were all 5/5 residents self advocating. In terms of advocacy home, B had the highest level of staff advocacy followed by A and D at 30% staff advocates, home C had 20% staff advocates, followed by homes E and F which were 100% resident self representing. 42 out of the 56 (75%) residents were self advocates, with one in four across the sample being represented by staff members.

Table 1: Selected Characteristics of the Homes, Staff and Service Users

Home	Residents with Learning Disabilities (participating in the study)	Self Advocacy by home	No of direct care staff	No of managerial staff	No of qualified staff	Residents attending Day Centres
A	24 (17)	12/17	7	2	3	24
B	15 (13)	8/13	5	2	3	15
C	9 (9)	7/9	4	3	1	9
D	8 (7)	5/7	4	2	1	6
E	6 (5)	5/5	3	1	2	6
F	5 (5)	5/5	3	2	1	5

The comparison normal population LEC sample of 410 adults consisted of randomly selected homes from a representative range of wards and this sampling strategy, across city and surrounding rural areas, was designed to represent diversity in income and ethnicity. Though socioeconomic status of

wards later correlated with LEC scores, more individual demographic data is unavailable (Ager, 2008).

The six homes met the following criteria:

1. The people living in the home did not change over the course of the study.
2. Data were available from all three of the phases of data collection.

Measure and Procedure

The Life Experiences Checklist (Ager, 1990, 1998) was completed for each person living in each home (subject to he or she having given consent, see participants section) at approximately six-monthly intervals. The LEC has five sub-sections (home, leisure, relationships, freedom and opportunities), each containing ten statements (e.g., Leisure: 'I do some sport at least once a month'). Respondents are asked to indicate which statements apply to themselves in a yes-no binary response format.

The numbers of statements in each section, which a person indicates as applying to themselves, are counted to give sub-section scores and summed to give a total score. Where possible, the LEC was completed by the author interviewing the participant alone; where communication difficulties between the researcher and the participant made this impossible, care staff were asked to be present to assist the person with an intellectual disability to answer or, if absolutely necessary, to answer on the person's behalf. The person with an intellectual disability was always present during the interview and was encouraged to participate to the maximum possible extent.

Feedback Process

After each six-monthly assessment period a simple feedback report was prepared and submitted in confidence, following ethical guidelines regarding particularly anonymity, to each individual home owner and manager. The reports presented the mean and range of the LEC domain scores for the home and included results for other quality measures taken but not reported here, these being results from the Activities of Daily Living Checklist (Davies, 1987), the Normalization/Environmental Measure (Beswick, 1989) and the results of a limited amount of direct observation (Repp, Felce and Karsh, (1991). Some of the reports included straightforward suggestions for possible avenues to improving quality such as staff training. Feedback reports were accompanied by an opportunity for the owner or manager to discuss the contents of the report with the present author.

Data Analysis

LEC sub-section mean scores for participants, and the percentage of the sample answering 'yes' to specific LEC items, were compared with the corresponding figures for a group of 410 householders living in the same county for whom data are provided by Ager (1998).

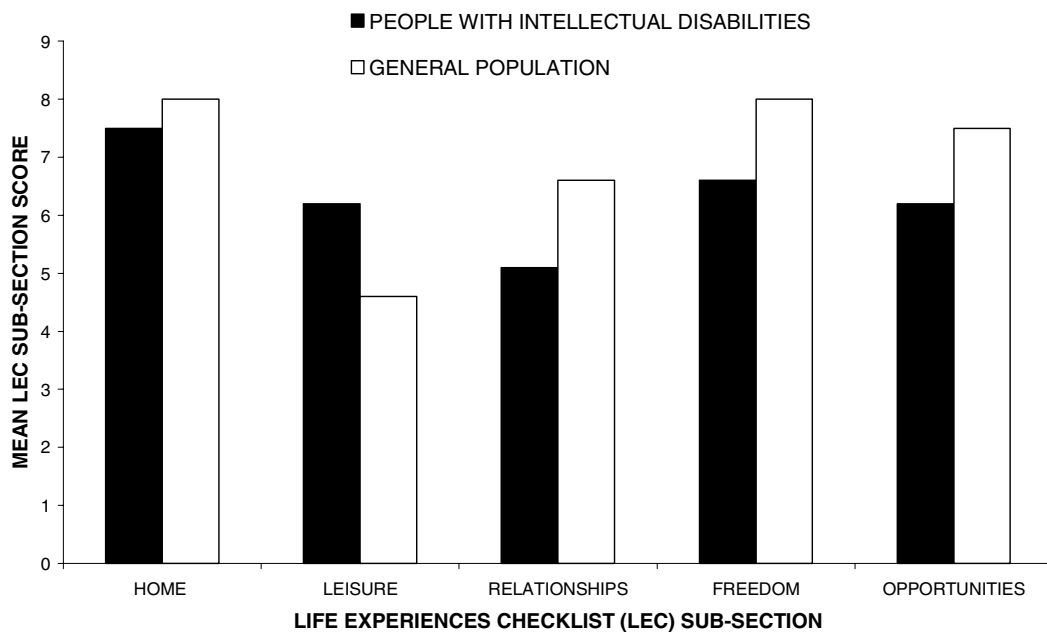
The reliability of changes in LEC scores over the three phases of the study was evaluated by repeated-measures analysis of variance using the 2V programme of the BMDP Statistical Software. An effect probability of less than .05 was required for the effect to be considered reliable.

Results

Figure 1 details LEC sub-section means for the sample of 56 participants with Learning Disabilities, from the first data collection phase, compared with the sample of 410 drawn from the randomly selected sample from the general population from the same County.

Possible scores in each domain range from zero to ten. The study sample had a mean 'home' score similar to that of the general population and had an average leisure score 1.6 points higher, than that of the general population. Mean domain scores were lower for the group with Learning Disabilities by 1.5 for relationships, 1.4 for freedom and 1.3 for opportunities.

Figure 1: Comparison of sample with normal population on LEC Sub-scales



Item by item comparison between the general population results for the LEC and results for the sample living in private homes showed some interesting differences in each domain.

Regarding the 10 items relating to the home on the LEC, only 52% of people with Learning Disabilities said their homes had 'more living rooms and bedrooms than people', vs. 79% in the general population, however, 23% more people with Learning Disabilities described their home décor as of "high standard" (96% vs. 73% in the general population). Weekly use of the telephone was rarer among people with intellectual disabilities (45% vs. 79% in the general population), as was having a room of one's own or shared with a partner only (50% vs. 88%).

The 10 item leisure section revealed more people with Learning Disabilities reporting at least monthly meals out at a café or restaurant (80% vs. 34%), at least monthly sporting activities (59% vs. 35%), at least monthly attendance at a club, class or meeting (84% vs. 35%), and having a hobby or interest (89%

vs. 63%). Fewer people with intellectual disabilities, however, reported 'weekly or more' social meetings with friends or relatives (57% vs. 70%).

The 10 items pertaining to relationships showed by comparison with the general population that less of the study sample reported having several close friends (55% vs. 78%). More reported being called by their first name by people living with them (98% vs. 68%), whilst no one reported being (including the 1:4 with advocates) as being 'sometimes addressed formally' (0% vs. 50%). Fewer described themselves as married or having a steady partner (7% vs. 70%), and fewer said they got on well with their families (64% vs. 88%). Both staying overnight with friends (18% vs. 47%) and having friends to stay (7% vs. 51%) were much less common among the group with Learning Disabilities.

In the 10 items under the freedom domain, the people with Learning Disabilities were much less likely than the general population to have participated in the choosing of home décor (13% vs. 84%) or to have chosen their own place of residence (52% vs. 76%). They were less likely to choose their own clothes (75% vs. 95%) and much less likely to have a vote (34% vs. 92%). A higher percentage of the group with Learning Disabilities said, however, that meal-times at home were changed to fit in with their plans (88% vs. 66%).

Regarding opportunities as measured, when compared with the general population, fewer of the group with Learning Disabilities participated in cooking (43% vs. 78%), and fewer could make snacks or drinks at all (55% vs. 94%), fewer engaged in housework (71% vs. 94%), and considerably fewer reported keeping a pet (4% vs. 46%). The sample, however, were more likely than the general population to report that they were being taught some new skill (45% vs. 23%), but much less likely to consider that their daily occupation was of help or value to others (21% vs. 70%).

Figure 2 shows the mean total LEC score for each home for each of the three phases of data collection. Repeated-measures analysis of variance showed a reliable main effect of phase of study ($F(2,100) = 4.53$) and a reliable home by phase interaction ($F(10,100) = 4.26$). For three homes (homes A, C and F), mean LEC score peaked at phase 2 and by phase 3 had declined to levels comparable to those of phase 1. One home (home B) showed little change in mean LEC score over the course of the study. Home D showed an increase in mean LEC score between phases 1 and 2 with the improvement maintained into phase 3. Home E showed no change between phases 1 and 2, but an increase in mean LEC score at phase 3.

Figure 3 shows the average score for each LEC sub-section for all participants in each phase of the study; it can be seen that the peak in total score at phase 2 is reflected in the score for each sub-section

Figure 2: Mean LEC Total Scale by Home and Phase

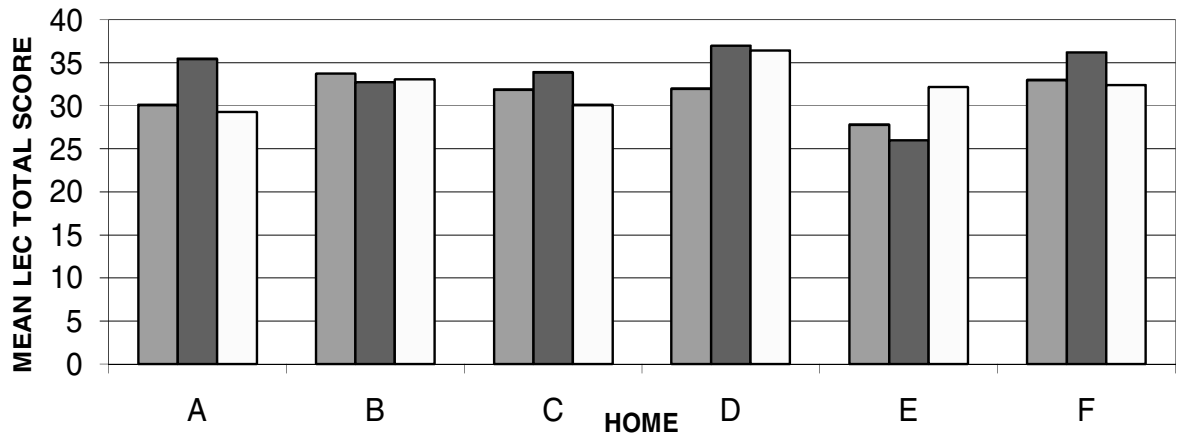
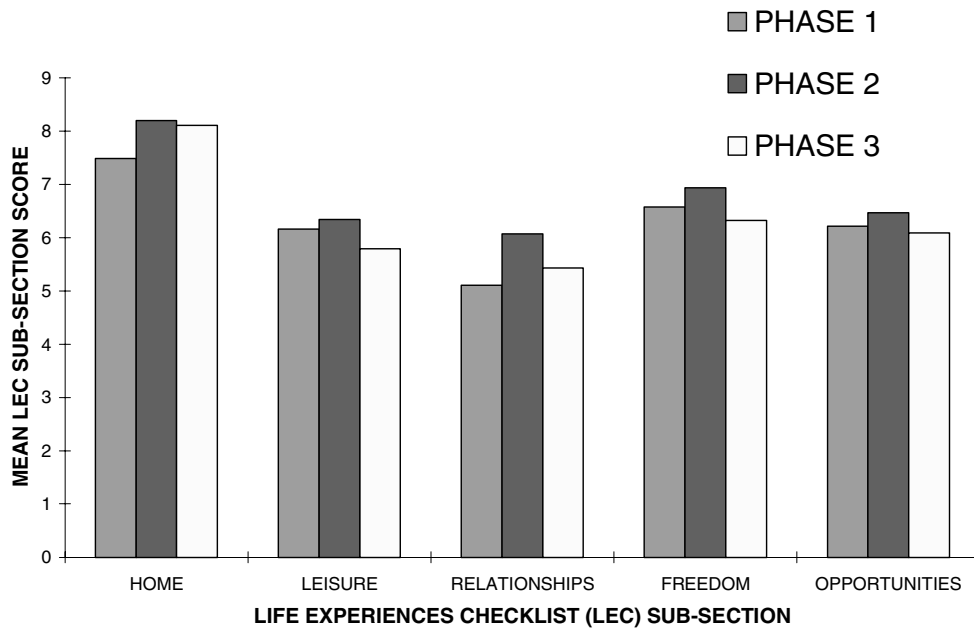


Figure 3: Mean LEC Sub-section Score by Phase



Ager (2008) points out that the sampling strategy of randomly selected homes by wards in the census was designed to sample across the city and surrounding rural areas, and to represent diversity in ethnicity and in the socioeconomic status of the 410 adult respondents; though no specific demographic data in terms of age and gender distribution is provided the comparison is still a useful, though tentative one, regarding the objective QoL available to the 56 adults in the study sample and that of the general population.

Given the possible effects of advocacy earlier reviewed, it should be acknowledged that the level of staff advocating for residents varied between homes, ranging from 40% in one home to full self advocacy in the two smallest homes and over the entire sample 3 out of 4 respondents were self advocates. Results in terms of reliability and reproducibility throughout the project should be treated with due caution, though more objective QoL measures (such as the LEC) have shown that objective life quality shows high levels of client-proxy agreement (Perry, Felce & Lowe, 2000).

Discussion

The aims of this study were to examine, over time, the quality of life experienced by people with Learning Disabilities living in private residential homes and to compare results with that of the general population as well as to, hopefully, enable the homes concerned to make positive use of the information gained through feedback.

The study sample, when compared with the general population, experienced a poorer quality of life in terms of measured indices of relationships, opportunities and freedom, though they had a comparable quality of home environment and scored higher than the general population in the leisure domain. This pattern of results is consistent with those arising from earlier studies of people with Learning Disabilities living in community settings (Ager, 1990; Ager et al., 2001).

The present results are specifically similar to those reported by Ager (1990) from two studies of people with Learning Disabilities living in 'medium' (7-12 places) and 'large' (24 places) community hostels. Other studies, with varying degrees of comparability with the present one, include that of Ager et al's. (2001) resettlement study from institutions to community based homes.

It is likely that a number of factors influenced the degree of involvement of people living in the homes in this study in various activities (Holland & Meddis, 1993). The overall picture compared to the general population, however, is clearly of a group of people with relatively few domestic responsibilities and weaker social networks, but engaged in relatively strenuous programmes of recreation and self-improvement. Important aspects directly related to the subjective features of quality of life included fewer social meetings with friends and family, reporting having close friends and fewer getting on well with their families, not staying out overnight with friends and having friends stay overnight. Regarding issues pertinent to human rights, fewer chose the décor within the place they lived and fewer had voted. The debateable comparative increase in leisure and self improvement is counterbalanced by poorer results concerning relationships and opportunities.

It is evident to the author that both subjective and objective indices are relevant in this study; a service user's satisfaction with life must surely include relationships with family and friends, since these are areas which appear to be important and predictable between studies of QoL in the normal population (Cummins 2005, Felce and Perry, 1995).

In the absence of controls, the cause of the change in LEC scores over time, with a peak at the second phase of data collection, cannot be identified with any certainty. It is possible that the provision of feedback reports on residents'

quality of life stimulated action from homeowners and managers. The reports were concise, simple, and in some cases made specific suggestions for action, often in the area of staff training. In reports scores were presented as percentage of a possible maximum. In some cases this format led owners and managers towards the conclusion that the reports were considerably critical of home functioning in certain areas, even where the results concerned were within ranges typical for people with Learning Disabilities living in residential services.

Alternatively, the evaluation process itself might have led to changes in residents' quality of life. Many LEC items raise explicit and objective questions about areas of life experience, and being asked such questions may have led both residents and staff of the homes to introduce changes. A third possibility, that the results are an artefact of increasing familiarity between the research interviewer and research participants, seems unlikely to explain the results given there was no simple trend over time.

In any event, the decline in LEC scores from phase 2 to phase 3 suggests that whatever the cause of the initial increase in scores, its effects were transitory and short lived in all but one home, home D. This home maintained the improvement in residents' quality of life initially observed for four out of the five homes. As can be seen from Table 1, the home was not obviously distinguishable from others in terms of size or staffing levels, expertise and had the 1:4 staff advocates reflected over the entire sample. Following receipt of the first individual report on their home, however, the owner-managers had requested training input on quality assurance.

Between phases 2 and 3 of data collection, a one-day 'quality workshop' was undertaken (not by the present author) which was attended by the owner-managers and their care staff. The workshop was based on the process outlined in the 'Guide to Quality Assessment' (Regional Mental Handicap Advisory Group, 1989), and includes sessions on defining the aims of the service, setting quality objectives, action planning, and monitoring progress.

The maintained improvement in residents' LEC scores in home D may, of course, be unconnected to the training and the owner's enthusiasm for training may both relate to other characteristics of the home. Given the current extent of private sector residential home provision in the UK, and the limited ability of registration authorities to influence service quality beyond minimum standards, quality action workshops may be worth evaluating, as a cost-effective way to enhance quality in this sector.

Results suggest that monitoring and feedback in isolation may not have a lasting effect and that more objective aspects of services may be relatively resistant to enduring change once established.

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