

CHANGES IN QUALITY OF LIFE FOLLOWING A MOVE FROM HOSPITAL TO A SMALL COMMUNITY UNIT FOR PEOPLE WITH LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR

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Introduction

Challenging behaviour has been partly defined in terms of its impact upon the quality of life of people with a learning disability. For example, Emerson *et al.* (1988) define challenging behaviour as:

'behaviour of such intensity, frequency, and duration that the physical safety of the person and others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities' (italics added).

Using such definitions evaluation of services to people with learning disabilities and challenging behaviour should not only consider changes in the level of challenging behaviour but also changes in quality of life. In this paper we illustrate the use of quality of life measures in the evaluation of special residential services for people with learning disabilities and challenging behaviour.

A range of services for people with learning disabilities and challenging behaviour have been reported (e.g. Fleming and Stenfert-Kroese, 1993). Here we are concerned with residential services. Data from the evaluation of the

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move from hospital to two specialised staffed homes each for four people with severe learning disabilities are reported by Emerson *et al.* (1992) and Mansell and Beasley (1990). They found that when people moved from the hospital there was an increase in staff time and facilities available to them in the home. The eight people were observed in contact with staff for a mean of 10.9% (range 3-23%) of the day; more staff attention was given to those people with the most severe challenging behaviour. The eight people spent a mean of 13.6% (range 8-24%) of their time engaged in constructive activity. Observation data were available for four people who were followed over two years, with measures from before and after leaving the hospital. After leaving the hospital two showed a fourfold increase in activity and two showed no changes in activity. The data presented in this and other studies show that engagement in activity and levels of challenging behaviour are not consistently improved when substantial environmental enrichment is achieved (e.g. Emerson *et al.*, 1992; Emerson and McGill, 1993). Several factors have been identified as mediating such results. In particular authors identify the importance of staff performance in ensuring that available opportunities are taken up and that structured intervention packages are carried out (e.g. Felce, 1993; Emerson *et al.*, 1992).

Direct observation of engagement and interaction has been a common measure of quality of services for people with learning disabilities with and without challenging behaviour in residential services. However, other measures have been used. For example, Murphy *et al.*

(1991) describe changes in the quality of life of people with mild learning disabilities and challenging behaviour in the Mental Impairment Evaluation and Treatment Service (Murphy *et al.*, 1991; Murphy and Clare, 1991). This study used the Five Accomplishments (O'Brien and Lyle, 1987) to organise measurement of quality of life. Measures were taken of the quality of relationships with staff, daytime activity, the quality of the environment, contact with family and friends and the use of seclusion. Most of these measures showed that the service achieved a higher quality of life than was available to people before admission. In an evaluation of specialist challenging behaviour services in Wales, Lowe *et al.* (1993) are using a range of measures of service quality; for example, activity within and outside the home, measures of staff stress and attitudes and measures of the quality of the social environment. Challenging behaviour has been defined in terms of its impact on quality of life (Emerson *et al.*, 1988; Blunden and Allen, 1987) and ensuring an improved and maintained quality of life may be a necessary (but not sufficient) component of residential services to people with learning disabilities and challenging behaviour.

In this paper are described changes in the quality of life of four men who moved from hospital to a small specialist community unit for people with learning disabilities and challenging behaviour. Measures were taken before they left the hospital and at three and fifteen months after they had moved. The model of quality of life has been derived from a normalisation perspective with emphasis upon activity and integration

within this. Therefore, the authors have completed a global normalisation based measure of quality of life to provide an overview of people's lives and added further detailed evaluation of activity within and outside the home.

Method

Subjects

The subjects are four men who moved from a hospital in the West Midlands during the final stages of closure in early 1992 to a small unit for people with challenging behaviour. Data from the Wessex Scale (Kushlick *et al.*, 1973) which is a brief disability rating scale and the Maladaptive Behaviour Inventory (MBI; Dagnan *et al.*, 1995b) were available for these men. The MBI has 15 items and has been shown to factor analyse into four scales; impulsive and aggressive behaviour, passive behaviour and lethargy, stereotypic and self-injurious behaviour, active social avoidance. TABLE I shows that the MBI identified no systematic change in challenging behaviour in the period of this study.

However, staff reported subjective improvements in the levels of challenge presented by the men. The four men are described briefly here.

FV is a 49 year old man with moderate learning disabilities who has been formally diagnosed as suffering from schizophrenia. He has several behaviours that challenge services but the one that is most difficult to manage is agitation. The Wessex scale suggests that he has no areas of substantial disability other than in challenging behaviour. FV was placed in an ordinary three bedroomed staffed house for six months in 1990. However, this placement broke down. He had lived in hospital for 39 years.

JK is a 39 year old man with moderate learning disabilities and some autistic behaviours. His greatest challenges are compulsive behaviours. The Wessex scale suggests that he has no areas of substantial disability other than in self-help skills and challenging behaviour. He had lived in hospital for 18 years.

JE is a 33 year old man with severe learning disabilities. His most challenging behaviour is smearing faeces. The Wessex scale suggests that he

TABLE I
Characteristics of Residents from the Maladaptive Behaviour Inventory

Maladaptive Behaviour Inventory	At Move				Mean	15 months post-move				Mean
	FV	JK	JE	FQ		FV	JK	JE	FQ	
Impulsive and aggressive behaviour	07	17	04	15	10.7	13	10	06	10	9.7
Passive behaviour and lethargy	09	11	06	05	7.2	10	09	07	11	9.2
Stereotypic and self-injurious behaviour	06	11	06	04	6.7	08	02	03	00	3.2
Active social avoidance	06	03	03	05	3.7	06	03	00	03	3.0
Total Scale	28	42	19	29	36.5	37	24	16	24	25.2

has no areas of substantial disability other than in verbal skills, self-help skills and challenging behaviour. JE was placed in an ordinary three bedroomed staffed house for 12 months in 1990/1991. This placement broke down. He had lived in hospital for 16 years.

FQ is a 57 year old man with severe learning difficulties. His major challenge is self-injurious behaviour. The Wessex scale suggests that he has no substantial areas of disability other than in verbal skills, self-help skills and challenging behaviour. He had lived in hospital for 48 years.

The ward and house

Before moving, the four men lived in the last remaining ward in a hospital that has now been fully closed. They lived there for a minimum of six months having been moved from other wards within the hospital as they were closed, or in the case of FV and JK having moved back to hospital from a community placement. The ward had been the home of five men, one man died one year after moving and his data are not included in this paper. The new home has six beds and is in a single storey complex of two other similar units. Two other men now live in the home but arrived after the first post-move data collection; data for these men are not presented. The other units in the complex are for older people with additional nursing needs. The unit was built on the edge of the hospital grounds, however, in the past 18 months the hospital has been demolished and a new housing es-

tate has been built on the site. The unit is in an affluent part of the borough of Solihull in the West Midlands. The home is staffed by nursing staff, clinical services are provided by Psychiatrists and Clinical Psychologists and an individualised day service is provided by social services staff (McEvoy *et al.*, 1993).

Quality of life measures

The Compass assessment

The global measure of quality of life used in this study is *Compass: A Multi-Perspective Evaluation of Quality in Home Life* (Cragg and Look, 1992). This is the most recent version of the *Questionnaire on Quality of Life* (Cragg and Harrison, 1986) which has been used in several British evaluation projects (e.g. Fleming and Stenfert-Kroese, 1990; Dagnan *et al.*, 1995a). *Compass* assesses the degree to which the lives of people with learning disabilities in residential provision are consistent with the Normalisation principles as set out in the five accomplishments (O'Brien and Lyle, 1987). The accomplishments are broad areas that are considered important in the lives of people with learning disabilities. The accomplishments suggest that services should ensure that people with learning disabilities maintain and improve a person's level of **activity and competence**, have **access to the community**, are given the opportunity to **make choices and decisions**, have the opportunity to make and maintain meaningful **relationships** and are given **status and dignity**. The *Compass* assessment includes one

additional accomplishment, that of enabling **individuality** (e.g. Blunden *et al.*, 1987).

Compass is divided into three parts. Part one is completed through interview with staff and residents, part two is completed through direct observation and part three is completed from the subjective impressions of the assessor. The questions in this measure are substantially the same as in the *Questionnaire on Quality of life* (Cragg and Harrison, 1986). The main difference is that the items are organised into scales representing the six accomplishments. Dagnan *et al.* (1994b) have described the inter-rater reliability of individual items and total scales for the original questionnaire which were very high. The 70 items had a mean inter-rater reliability of 0.64 (SD = 3.1) for Kendall's Tau and 78% (SD = 15%) for percentage agreement.

Diary records of activity

Each diary consisted of a front page upon which were the resident's name, and instructions for its completion. The instructions asked for a record to be made of every occasion that the resident left the home. The rest of the diary consisted of one page per day with headings for trip destination, duration, type of transport and company on the trip. These diaries have been used successfully in a number of previous evaluation studies (Dagnan and Drewett, 1992; Dagnan and Drewett, 1994; Dagnan *et al.*, 1994a). Dagnan *et al.* (1994a) showed that a one week diary was sufficient to produce an accurate representation of

routine activity outside the home for people living in hospital and community based homes.

Direct observation

To measure the activity of people within the home direct observation was carried out with a 10 second momentary time sample. The behaviour categories used were based upon those described by Mansell *et al.* (1982). The schedule has codes for whether the person was actively engaged with the environment and if so what they were doing, and whether they had any verbal or physical contact with staff or other residents.

Procedure

The Compass assessments were completed by an assistant psychologist at pre-move and at 3 months post-move and by a different assistant psychologist at 15 months post-move.

The activity of the residents, when outside the home, was monitored by staff who completed a diary for each resident for one week (Friday to Friday) before moving in February 1992 and for one week 3 and 15 months after moving.

Observations were made before moving during February 1993 and at 3 and 15 months after moving. The observations were made at early and mid-morning, just before lunch, during lunch, immediately after lunch, and after the evening meal. Each period of the day was sampled from a different day of the week. This approach to sampling the day has been shown to produce

representative data for direct observation methods (Landesman, 1987). Each observation consisted of 10 minutes of momentary time sampled observations with a 10 second inter-observation interval per person. The observers were in the house for 30 minutes prior to making the observations so that the residents got used to them being there. Observations were not made in bedrooms or toilets.

The observations were carried out by an assistant psychologist at a pre-move and first post-move data collection and by a different assistant psychologist at the second post-move data collection. For reliability purposes the two observers simultaneously observed a video of people with challenging behaviour for a total of 50 minutes. Reliability for the data categories presented in this report was calculated using Kappa (Cohen, 1960). Kappa values were 0.78 for the categories of engaged behaviour and 0.82 for whether or not contact was present.

Results

The Compass Survey

TABLE II shows the percentage of the possible total score in each of the six accomplishments at all three data points for the four men. A great deal of detailed information can be obtained from the Compass, however, this is lengthy and is not reported here.

Diary records of activity

The diaries of activity outside the home provide information about the physical integration of the residents.

The number of trips made and places visited

TABLE III shows that since the move many more unsegregated facilities are used. This is a particularly important

TABLE II
Mean and Individual Scores for the Six Accomplishments Taken from the Compass Quality of Life Assessment

Compass Accomplishments	Pre-move % of possible total score		Post-move 1 % of possible total score		Post-move 2 % of possible total score	
	Compass Scores for Four Men FV JK JE FQ		Compass Scores for Four Men FV JK JE FQ		Compass Scores for Four Men FV JK JE FQ	
		Mean		Mean		Mean
Activity	20,25,21,25	22.7	68,74,68,74	71	54,51,57,62	56
Community Access	58,58,58,58	58	58,58,58,58	58	52,52,52,56	53
Community Relationships	09,08,08,08	8.3	28,50,30,56	41	30,27,24,33	28.5
Dignity	30,32,34,38	33.5	64,66,62,70	65.5	56,54,56,54	57.5
Choice	20,25,21,26	23	57,58,50,58	55.7	49,52,49,58	52
Individuality	25,28,26,32	27.5	58,60,55,72	61.3	54,49,60,62	56.3

facilities and a slight increase in the number of maintenance activities. In the last year there has been a slight drop in the number of leisure trips but considerable increases in the number of work/education and maintenance trips.

Direct Observations

Engaged behaviour

TABLE IV shows the amount of engaged behaviour before and after the move. This shows that there has been a substantial increase in the amount of time residents are engaged. Within the engagement category there has been an increase for leisure activity at 15 months post-move, a small overall increase in domestic activity, an increase in personal activity at 3 months post-move and an initial decrease in contact.

At all three observations points most contact was with staff.

Discussion

The study has shown that the quality of life of four people with learning disabilities and additional challenging behaviours has improved substantially following a move from hospital to a small specialist community based home. In particular, positive changes have taken place in the three accomplishments of **Activity, Choice and Dignity**. In the area of activity staff have maintained a positive approach about the potential of residents to achieve skills. Regular activities are well established with

timetabling having improved between the two post-move data collections. Residents are making regular use of non-segregated community facilities. Choice has improved, with residents now having choice over the internal decorations of the home, what to wear each day, when and upon what to spend money and over menu planning and food purchasing. Dignity has improved, with residents now having greater privacy, more personal possessions and a general higher quality of environment. The diaries show that during the last 15 months there has been a substantial increase in the **number** of trips and in the use of **non-segregated** facilities. There was an initial increase in the **variety** of facilities used by the men, and this has been maintained to 15 months post-move. One of the most notable changes 15 months after the move is that the number of maintenance trips made by the residents has risen very substantially. The residents now make at least three trips in a week, and make as many maintenance trips as work and educational trips. Leisure is still the most frequent reason trips are made. There are still less trips made to work and educational facilities than were made pre-move. However, this reflects a closer collaboration between residential and day services. Prior to moving any trip to day services was classified as work and education. Now, many trips are made with day service staff directly from the home and so appear as a different category of activity. Direct observation also shows that residents have increased the percentage of their time that they were engaged in purposeful activity. Much of

this reflects an increase in leisure at 15 months post-move and an increase in personal activity at 3 months post-move. Whilst the aims of a particular service may give different priorities to some areas of quality of life it is an important goal for people with challenging behaviour. A key finding in the present study is that it is possible to improve the quality of life of people with learning disabilities irrespective of changes in levels of challenging behaviour. Using the Emerson *et al.* (1988) definition of challenging behaviour this suggests that the service has effectively altered the impact that this behaviour has on the subjects' quality of life.

Although this study has used some quality of life measures not previously reported in the evaluation of services for people with challenging behaviour, there are a number of aspects of quality of life that have not yet been used. One difficulty in identifying appropriate measures is that few studies have used explicit models of quality of life in identifying service goals. A number of such models are available. For example, Felce and Perry (1995) present a model of quality of life that integrates objective and subjective indicators. In this model quality of life is viewed from three standpoints; objective life conditions, personal values and aspirations, and subjective feelings of well-being and satisfaction. Felce and Perry identify five domains that may be measured from each standpoint; physical well-being, material well-being, social well-being, development and activity and emotional well-being. Using this framework it is evident that quality of life measures

used in the evaluation of specialist services for people with challenging behaviour have been relatively limited both in the domains used and standpoints adopted. In particular future evaluations might consider using measure of less frequently reported quality of life domains such as social well-being, development and activity and emotional well-being and from the standpoint of personal aspirations and subjective feelings of well-being and satisfaction. Quality of life has been identified as an important goal of services to people with learning disabilities and a better definition of what this entails would enable services to be evaluated and provided more effectively.

Summary

This paper has shown that there has been an increase in the quality of life of four people with learning disabilities and additional challenging behaviours following a move from hospital to a small specialist community based home. Particular increases were noted in the normalisation based accomplishments of Activity, Choice and Dignity. There has also been an increase in the amount of activity outside and within the home and in the frequency of use of unsegregated facilities. A good quality of life is an important goal for residential services for people with learning disabilities and challenging behaviour that may be achieved independently of changes in the severity of challenging behaviour.

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