

## A PILOT STUDY OF THE USE OF THE SF-36 TO ASSESS HEALTH STATUS OF ADULTS WITH LEARNING DISABILITIES LIVING IN SMALL COMMUNITY BASED HOMES

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### Introduction

The physical and mental health needs of people with learning disability have received increasing research attention (e.g. Larson and Lapointe, 1986; Edgerton *et al.*, 1994; Moss *et al.*, 1993; Kerr *et al.*, 1996; Bouras, 1994; Borthwick-Duffey and Eyman, 1990). Studies describe the level of physical health need in populations of people with learning disabilities, often with comparisons to other populations. For example, Beange *et al.* (1995) studied 202 randomly selected people with learning disabilities living in Northern Sydney. The group had higher rates of medical consultation and hospitalisation than found in the local population of people without a learning disability. Medical examination detected a mean of 5.4 medical problems for each person, around half of these had not been previously identified. Other

studies compare across settings for people with learning disabilities. Rimmer *et al.* (1995) studied the health of people living in institutions, group homes or with families. They found that people living in group homes used more alcohol, coffee and cigarettes and took less exercise than people living in institutions and with families. British studies have often been based upon records from existing data such as population registers or clinical records, as health status questionnaires suitable for use with people with learning disabilities are not widely available (Hogg *et al.*, 1988). Studies of the mental health status of people with learning disabilities identify high levels of prevalence. For example, Borthwick-Duffy and Eyman (1990) found that 10% of people with a learning disability served by one American state were diagnosed as having a significant 'mental illness'. They found a tendency

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for people with mild learning disabilities to be more likely to be identified as having a psychiatric disorder.

Few studies have examined the impact of the physical and mental health of people with learning disabilities on their social and physical functioning. It is important for health services to ensure that primary and other health care is accessible and appropriate for people with learning disabilities (e.g. Kerr *et al.*, 1996; Edgerton *et al.*, 1994). However, it is also important for services to maintain the level of life quality of people with learning disabilities when their level of health need changes through ageing or other problems associated with learning disability. The increased longevity of people with learning disabilities makes the increased presence of some physical problems more likely. Thus it is particularly important that scales are available that can identify the impact that health has on life quality.

The SF-36 Health Survey Questionnaire (Ware, 1993) is a tool that has been developed to monitor the impact of a person's physical and mental health on their social and physical functioning. The scale has eight subscales that measure physical functioning, the impact of physical and mental health on work or other activity, bodily pain, general health, vitality, social functioning and mental health. TABLE I shows the eight subscales of the SF-36 with a brief description of their content areas.

The psychometric properties of the SF-36 have been established in a large number of studies of people without learning disabilities (Stewart and Ware, 1992). It has been the subject of a number of British standardisation studies (e.g. Brazier *et al.*, 1992; Jenkinson *et al.*, 1993; Garratt *et al.*, 1993). For example Brazier *et al.* (1992) studied 1582 general practice patients in the UK. They found the SF-36 to have high internal, test re-test and

**TABLE I**  
**Description of SF-36 Subscales**

<b>Subscale</b>	<b>Description</b>
<b>Physical Functioning (PF)</b>	Performance of physical activities such as self-care, walking, climbing stairs and vigorous activities.
<b>Role-physical (RP)</b>	Effect of physical health on work and/or other daily activities.
<b>Bodily Pain (BP)</b>	The intensity, duration and frequency of bodily pain and limitations in usual activities due to pain.
<b>General Health (GH)</b>	The beliefs and evaluations of a person's overall health, including current and prior health, health outlook and resistance to illness.
<b>Vitality</b>	<i>Feelings of energy, fatigue and tiredness.</i>
<b>Social Functioning</b>	Extent and frequency of health problems interfering with normal social activities.
<b>Role-emotional</b>	Effect of emotional health on work and/or other daily activities.
<b>Mental Health</b>	A person's emotional, cognitive and intellectual status.

alternate form reliability. Concurrent validity has been established showing the measure to have strong relationships to other measures, such as the Nottingham Health Profile (Brazier *et al.*, 1992), the Shortened Arthritis Impact Measurement Scales (Katz *et al.*, 1992). The hypothesised structure of the SF-36 has been tested using factor analysis (Ware, 1993). The scale has been constructed to measure physical and mental health and it has been shown to have a two factor structure indicating one physical and one mental factor (Ware, 1993). Physical functioning, role physical and bodily pain load on the physical factor, mental health, role-emotional and social functioning load on the mental factor, vitality and general health perceptions load on both factors.

The SF-36 has not previously been used with people with learning disabilities and there are currently no studies that have reported adapting the scale for completion by a third party. The purpose of this study was to examine the psychometric properties of this scale when used in a third party format with direct carers of people with learning disabilities living in small community-based homes.

## Method

### *Participants*

The participants were 71 people with learning disabilities; these are all the people with learning disabilities living in the 18 community homes in one NHS trust. The group was made up of 56 (79%) men and 15 (21%) women and had a mean age of 59.7 years (SD = 16.7),

with a range of 21.6 to 93.6 years. Sixteen people are in the age band from 20 to 49 years, 36 from 50 to 69 years and 19 are over 70 years. The participants were rated on the Wessex Scale (Kushlick *et al.*, 1973) which is a brief disability rating scale that has been widely used in British studies. The characteristics of the participants using scales derived from the Wessex Scale are presented in TABLE II. The participants live in 18 community-based houses, of these 2 houses are for 6 people, 11 are for 4 people and 5 are for 3 people.

### *Measures*

For the purpose of this pilot study the SF-36 (Ware, 1993) underwent minimal adaption. Questions were simply rephrased from 'do you . . .?' to 'does the target person . . .?'.

### *Procedure*

The key worker for each participant was asked to fill out the SF-36 and the Wessex Scale. Thirty six people with learning disabilities were rated by 2 staff members in order to calculate the inter-rater reliability of the scale.

## Results

The mean percentage scores for each subscale and the total scale are shown in TABLE III.

**TABLE II**  
**Characteristics of all Residents Using Categories Derived from the Wessex Scale.**

	<b>n</b>	<b>%</b>
<b>Self-help Skills</b>		
Full self-help skills	30	(42.3)
Some self-help skills	34	(47.9)
No self-help skills	7	(9.9)
<b>Literacy</b>		
Literate	7	(9.9)
Partly literate	4	(5.6)
Not literate	60	(84.5)
<b>Mobility</b>		
Full ambulant	48	(67.6)
Partly ambulant	15	(21.1)
Not ambulant	8	(11.3)
<b>Continence</b>		
Fully continent	44	(62.0)
Not fully continent	27	(38.0)
<b>Sensory Disability</b>		
No sensory disablement	37	(52.1)
Some sensory disablement	34	(47.9)
<b>Verbal Skills</b>		
Not verbal	15	(21.1)
Partly verbal	19	(26.8)
Verbal	33	(46.5)
<b>Behaviour Disturbance</b>		
No behaviour disturbance	44	(62.0)
Mild behaviour disturbance	23	(32.4)
Severe behaviour disturbance	4	(5.6)

**TABLE III**  
**Mean Percentage Scores and Inter-rater Reliability for the SF-36**

	<b>No. of Items</b>	<b>Mean Score</b>	<b>SD</b>	<b>Inter-rater Reliability Pearson's r</b>
Physical Functioning	10	50.5	34.0	0.89
Role-physical	4	66.6	42.3	0.44
Bodily Pain	2	72.2	24.2	0.60
General Health	5	56.2	25.4	0.67
Vitality	4	58.1	21.4	0.69
Social Functioning	2	80.2	20.9	0.54
Role-emotional	3	78.4	38.7	0.31
Mental Health	5	73.1	15.4	0.63
<b>Total</b>	35	533.1	247.5	0.63

### *Inter-rater Reliability*

Thirty six people with learning disabilities were rated by 2 staff members who had known the target person for some time and included their key-worker. Rater group 1 had known the target person for a mean of 3.3 years (SD = 2.5) and rater group 2 had known the target person for a mean of 4.4 years (SD = 3.7). The mean time between completion of rating scales for each target person was 4.0 days (SD = 3.7), the maximum time between ratings was 14 days. The 36 participants who were rated twice for the purposes of the reliability study was made up of 29 men (81%) and 7 (19%) women, they had a mean age of 57.2 years (SD = 18.0), their ages ranged from 21.6 to 88.9 years. The reliability group did not differ from the larger participant group on these variables.

TABLE III shows the inter-rater reliability for each subscale calculated using Pearson's *r*. It can be seen that moderate reliability is achieved, however, the role-physical scale and the role-emotional scale are considerably less reliable. The

level of reliability evident with the third party version of this scale is such that it would not be useful for comparison across individuals but is within the range required to make group comparisons (Nunally, 1978).

### *Internal Reliability*

TABLE IV shows the alpha coefficients and item-total point biserial correlations for each subscale. Again the levels are largely acceptable with the exception of the social functioning scale where both the mean item-total correlations and alpha are low.

### *Factor Structure*

The SF-36 subscale scores were subjected to a principle components factor analysis followed by a Varimax rotation replicating the analysis reported by Ware (1993). TABLE IV shows the obtained two-factor solution. The factors can be clearly interpreted as a physical

**TABLE IV**  
Internal Reliability and Factor Structure of the SF-36

	No. of Items	Alpha	Item-total Correlations		Factor 1	Factor 2
			Mean	SD		
Physical Functioning	10	0.94	0.76	0.09	<b>0.59</b>	0.14
Role-physical	4	0.91	0.80	0.05	<b>0.78</b>	0.18
Bodily Pain	2	0.88	0.79		<b>0.75</b>	0.25
General Health	5	0.87	0.60	0.12	<b>0.83</b>	0.03
Vitality	4	0.81	0.63	0.02	0.47	<b>0.62</b>
Social Functioning	2	0.33	0.19		0.42	<b>0.58</b>
Role-emotional	3	0.93	0.85	0.04	0.18	<b>0.75</b>
Mental Health	5	0.71	0.49	0.16	-0.06	<b>0.90</b>
<b>Total</b>	35	0.92	0.50	0.14		

health factor (factor 1) and a mental health factor (factor 2) with vitality and social functioning loading mainly on the mental health factor but having a reasonable loading on the physical health factor. This factor structure replicates that presented by Ware (1993).

same age band from a British standardisation study (Brazier *et al.*, 1992). FIGURE 1 shows a profile for the group compared with the profile expected from the standardisation data. It is not possible to statistically compare these data as Brazier *et al.* (1992) does not present standard deviations for his data set.

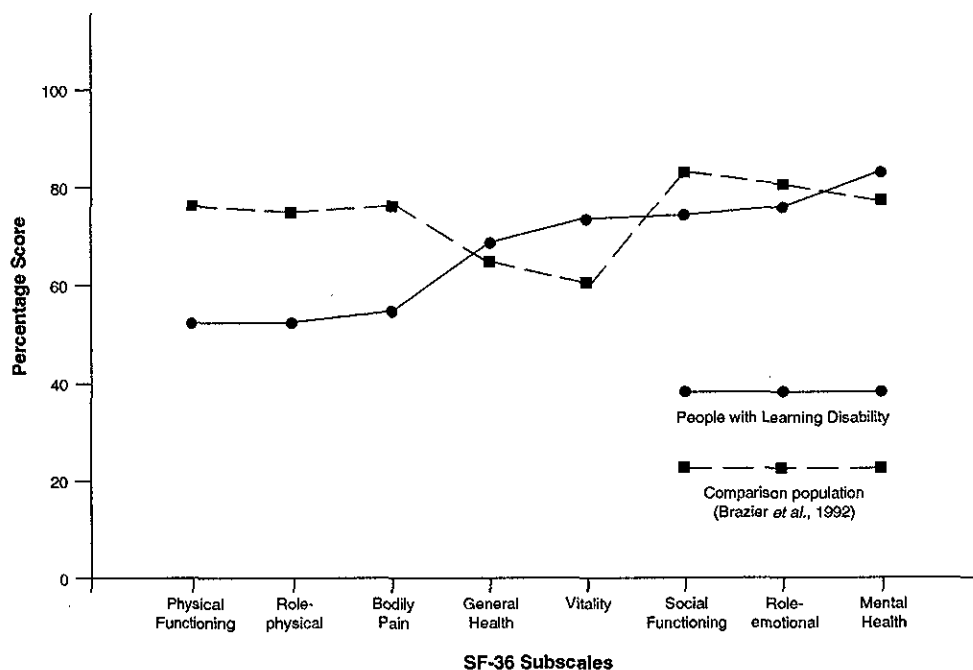
### Comparison with Norms for SF-36

The SF-36 subscales are calculated using percentages (Ware, 1993) and scores can be compared to the population norms published for the scale. In order to illustrate this we compare here the 20 people who fall in the study group modal age band 55-64 with the

### Discussion

This paper has reported a pilot study of the use of the SF-36 (Ware, 1993) in a third party format with carers of people with learning disabilities living in small community homes. The psychometric properties of the scale have been

**FIGURE 1**  
Profile Comparing Data from 55-64 Year Old Age Group in Present Study to Comparison Data for Similar Age Group without Learning Disability



reported. The internal reliability of the scale is acceptable and its factor structure replicates the reported structure of the scale when used in its first party format. The factor structure obtained in the present study is more clearly a 2 factor solution than that described by Ware *et al.* (1993). However, those items that are reported by Ware (1993) to load on both factors do so to a similar extent in the present study with the exception of general health which, in the present study, clearly loads with the physical health factor. A simple comparison was made between the scores for the modal age band of participants in the present study and a comparison group of people without learning disabilities. Although, the significance of differences cannot be established the largest differences are evident in the scales of physical functioning, the impact of physical health on activity and bodily pain.

This paper presents the first reported use of this scale with third party informants. Other scales use carers as informants in measuring experiences that may be considered to have a subjective element. For example, scales assessing quality of life (e.g. Schalock *et al.*, 1990; Cragg and Harrison, 1986) have been used with staff as informants. There is little study of the systematic bias that may be involved in using such scales in this way. Thus, establishing the inter-rater reliability of the scale when used for third party informants has been particularly important. In this data set most of the scales have a Pearson's  $r$  for inter-rater reliability above the 0.5 level considered necessary if the scale is to be used to describe health status scores for groups of people (Nunally, 1978). The inter-rater reliability achieved for the

role-emotional and role-physical scales falls below this level. The items in these scales rate the degree to which physical and emotional health have affected the time spent, accomplishments and care taken in work and other activities. This is a complex judgement for carers to make, particularly considering that no participant has a work placement. The scales that may have been expected to cause most problems in inter-rater reliability, such as the mental health scale have an adequate inter-rater reliability. Previous work has questioned the ability of carers to report on the emotional experience of people with learning disabilities. For example, Clark *et al.* (1991) have found that staff do not agree on the signs that they use in deciding that a person is expressing sadness. However, in this scale staff are quite reliable in a series of judgements of general emotional states for the people they work with. One of the strengths of the original scale is that it is completed by the patient rather than the physician. Further study should be carried out to compare carer report with report from people with learning disabilities using the scale. However, in order for the scale to be widely used by people with learning disabilities it would need considerable adaptation.

The scale measures an important aspect of the health related functioning of people with learning disabilities that is not measured in other scales for people with learning disabilities. This makes its use as a third party instrument worth exploring. Social functioning and well being are important components of quality of life (e.g. Felce and Perry, 1995) and previous studies have shown that age and disability do impact upon quality of life of older people with learning

disabilities (Jones *et al.* in press). Scales that directly measure this interaction between health status and quality of life are useful additions to the range of disability and quality of life assessments available for use with people with learning disabilities.

## Summary

This paper describes a pilot study of the use of the SF-36 to describe the health of people with learning disabilities. The scale was adapted for use by third party informants and completed for 71 people living in small community homes in one Health Trust in the UK. The adapted scale has good internal reliability and a factor structure that is similar to that of the original scale. The inter-rater reliability of the scale is generally at a level that would suggest it is suitable for use in describing the health status of groups of people with learning disabilities. Scores obtained in this study are compared to norms for a similar age band comparison group of British people without learning disabilities. The importance of having scales that assess impact of health upon the lives of people with learning disabilities is discussed.

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