

STEPS TOWARDS NORMALIZATION: A REVISION OF "39 STEPS"

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McCormick *et al.* (1975) stated "that the behaviour of institutionalised retarded persons is influenced by the institutionalisation which they experience rather than being completely determined by their mental retardation *per se*". From views similar to this there has been pressure to create conditions for the mentally handicapped which are as "normal" as possible in order to give the handicapped opportunities to absorb and adapt to them at their own speed. The philosophy is enshrined within the Declaration of the Rights of Mentally Handicapped people adopted in 1971 by the United Nations Organisation. It indicated agreement on the right of the mentally handicapped person to be treated as any other adult, and thus the right to live in as normal an environment as possible. In the United Kingdom this is endorsed within the Jay Committee Report (1979) where it is recommended that care staff should be trained so that they can create a normal life style. Nirje (1973) saw the normalization principle as implying normalization of the total environment, of the activities, and the atmosphere surrounding the mentally handicapped person, so that life in the community becomes more understandable. It follows that normal adaptive behaviour cannot be encouraged in abnormal conditions such as a large hospital or segregated educational facilities (Gunzburg, 1974).

There have been several checklists devised to highlight institutional practices: Elliott (1975); Model Standards Document, DHSS (1978); National Development Group for the Mentally Handicapped (1980).

Generally the intention of these checklists has been to promote discussion of the points of institutionalisation which should then be changed. A serious disadvantage is that most of them take such time and co-operative effort to complete that they are used irregularly and unsystematically. If comparisons are going to be made between institutions or if changes within an institution can be judged significant, the components of institutionalisation need to be quantified and scaling or measurement becomes necessary. Two checklists or inventories which have measured institutionalisation in hospitals for the mentally handicapped are the Child-Care Management Inventory (King *et al.*, 1971) and the Thirty-nine Steps Checklist (Gunzburg, 1973).

The Child Management Inventory consists of 30 items. Each item is scored on a three point scale. A score of 0 indicating child orientation; a score of 2 indicating institutional orientation; a score of 1 indicating a mixed pattern. The authors placed the items in groups to indicate four main characteristics of institutionalisation — Rigidity of Routine, 'Block Treatment', Depersonalisation and Social Distance. However McCormick *et al.* (1975) who had adapted the CMI for use with adults found no evidence that the inventory measured these four factors. Nevertheless, King *et al.* (1971) found striking differences between various residential facilities for normal and handicapped children giving some validity to the quantification of institutionalisation. Some of the items have become out-of-date over the years e.g. the conveyor-belt system of bathing and toileting, visiting time, walking in crocodiles rarely exist so that the scale needs revision.

Thirty-nine Steps

Gunzburg had not intended that the "39 Steps leading towards normalised Living Practices in Living Units for the mentally handicapped" be used as a scale but the items

lend themselves to scaling. Each practice could be scored as institutional (0) or normal (2) e.g.
Item: Bed time

- a. is regular and determined by the night staff (score 0)
- b. is by and large left to the residents' discretion (score 2)

and if both practices prevailed in the unit, as a result of differences between staff shifts, or because some patients could be left to decide for themselves (score 1)

The 39 Steps has been used with facility in Somerset as a regular tool for monitoring and research (May *et al.*, 1978; May and Howell, 1979; Howell and May, 1980) but it needed some revision as a psychometric instrument, because May *et al.* (1978) reported an inter-rater reliability coefficient of only +.59, its validity was unknown and because it had potential for monitoring residences for the elderly and mentally ill if some of the items were re-worded.

An item analysis of the original 39 Steps was made from data collected in 27 Social Service and NHS residences for the mentally handicapped in Somerset. This demonstrated that some items were endorsed just as frequently in residences which attained a high score as those which scored low overall on the 39 Steps. These items were dropped, reworded or replaced with others considered pertinent.

This second edition of the 39 Steps was administered in 20 Social Service or NHS residences for the mentally handicapped drawn from four counties in South West England. Another item analysis was performed and nine items were dropped.

The residual items (see APPENDIX) formed the third version of Gunzburg's 39 Steps, but as the 39 was reduced now to 30 it was retitled "Gunzburg's Steps List".

Inter-Rater Reliability

The "Steps" list was completed twice in 22 residences for the mentally handicapped from, as before, both Social Services and NHS. The list was completed each time by the person in charge or a deputy independently. The psychologist only interviewed at the end if a question posed particular difficulty. The total score on the "Steps" list for the first testers was correlated with that of the second testers. The Pearson product moment correlation was +.93, a satisfactory level of reliability. The "Steps" list was also completed twice independently in 19 wards of a mental illness hospital, and the Pearson correlation was +.95.

Construct Validity

If the "Steps" list is measuring institutionalisation then it should discriminate between units for the mentally handicapped which are within large institutions and autonomous units. In this study the autonomous units were considered to be the Social Service hostels in the community and the hospital training flats, where people are moved prior to living in the community. The "Steps" list scores for these 8 units were compared with those from the remaining 27 hospital wards i.e. institution units. There was a significant difference between the means ($t=8.85$ $p<.01$) of 52.7 for the autonomous and the 23.5 for the institution units on the "Steps" list scores.

Concurrent Validity

Concurrent validity was also evaluated. Raynes *et al.* (1979) reported a very strong relationship between the quality of care and resident competence levels. It would be predicted then that there should be a significant association between "Steps" list scores for a unit and the general level of dependency or competence exhibited by the residents within that unit. This general level of dependency was determined by the staff:patient ratio

necessary for each unit. These figures are prepared annually in Somerset for planning purposes (May *et al.*, 1982) after all the patients in the mental handicap hospitals have been assessed for dependency on the Wessex Mental Handicap Register (Kushlick, 1973). Twenty-eight out of the total of 29 possible units in Somerset were included (one was omitted because it had been divided after the dependency study). The Spearman Rank Order Correlation was $=.73$ $p < .01$.

DISCUSSION

The "Steps" list now has a satisfactory inter-rater reliability, construct and concurrent validity. It can be used to compare units or to see if they have become less institutional over time. It can also be used to see if institutionalisation is related to other variables such as the incidence or prevalence of disturbed behaviour. Furthermore the items have been phrased so that the list can be used to assess other residential settings such as wards or hostels for the elderly as well as those for the mentally handicapped.

SUMMARY

A scale is described for quantifying institutionalisation. Derived from Gunzburg's "39 Steps towards normalization" this revision has improved reliability and validity.

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APPENDIX

Gunzburg's Steps List — a revision

(N.B. The scoring suffixes would normally not appear on the list)

These questions assess the living practices in Units for people with disabilities. Please tick whichever practice prevails in your Unit. *If both occur tick both.*

1. Friends and visitors are invited back to the unit for meals
 - a. rarely (less than once a month) 0
 - b. frequently (more than once a month) 2
2. Bedtime
 - a. is by and large left to the residents discretion 2
 - b. is regular and determined by the night staff. 0
3. Sundays
 - a. give opportunities for lying in a little longer 2
 - b. follow the same pattern as weekdays — same getting-up time etc. 0
4. Annual holidays are organised
 - a. for the unit as a whole 0
 - b. for individual residents or small groups 2
5. Light fittings
 - a. are domestic looking, different lights supported by table and standard lamps, wall brackets, etc. 2
 - b. are of the fluorescent bar type and uniform throughout the Unit 0
6. Living Room
 - a. contains generally chairs, tables, television, ashtrays 0
 - b. contains a sideboard, bookshelves, fishtank, table lamps, or other furniture as well as chairs, tables, television, ashtrays 2
7. Chairs in sitting room (day room)
 - a. are more or less of identical shape and design and placed in rows mainly along the walls 0
 - b. are of varying shapes and colours, grouped pleasingly and invitingly 2
8. Bedrooms
 - a. are for one or two persons only 2
 - b. are dormitories for three or more people 0
9. Living space
 - a. some areas are restricted e.g. unit office, staff toilets, staff rest room, bedrooms during the day 0
 - b. is freely accessible to all residents (though particular items are kept under lock and key e.g. medicine cupboard, lockers, desk) 2
10. Dressing tables, chest of drawers, etc.
 - a. are generally bare with no personal possessions 0
 - b. are generally exhibiting a full show of personal "knick-knacks" 2
11. Furniture in bedrooms
 - a. shows available domestic variety 2
 - b. is of the same pattern throughout (e.g. lockers, wardrobes) 0
12. Mirrors
 - a. including one full length mirror are provided in bedroom, bathroom and near the front door 2
 - b. are only in the bathroom 0

13. Bedspreads	
a. are uniformly of the same colour and material throughout the Unit	0
b. are of different patterns, material and style and provided for residents individually	2
14. Best clothes	
a. are freely accessible to residents	2
b. are only obtainable through the staff	0
15. Residents' pocket money is	
a. kept in the office, and handed out when required	0
b. kept by residents themselves	2
16. How pocket money is distributed	
a. handed out to residents to put into own purses	2
b. put into residents' purses by staff, and kept in the office	0
17. Staff are having meals more than once a week with the residents	
a. No	0
b. Yes	2
18. Staff	
a. wear uniform or identical overalls	0
b. wear their private clothes or overalls or house dresses of different design and pattern	2
19. Residents	
a. are responsible for their own "private corner" (including bedmaking) even though communal areas are cleaned by staff	2
b. are not required to look after their own area (e.g. bedroom) which is cleaned etc. by domestic staff	0
20. Personal possessions in wardrobes and chest of drawers	
a. are looked after by the residents	2
b. are regularly sorted out by staff to avoid accumulation of rubbish	0
21. Breakfast	
a. is a set meal provided by the central kitchen	0
b. can be individually chosen from food cooked or prepared in the unit	2
22. Residents' private food supplies (e.g. orange squash, cocoa, biscuits)	
a. are generally absent	0
b. are present in kitchen cupboards, fridge or lockers	2
23. After meals	
a. the residents leave individually (though perhaps observing the common courtesy of waiting till everyone at the table has finished)	2
b. the residents wait until told to go	0
24. At mealtimes, vegetables, potatoes, etc.	
a. are handed out in portions (whether as a plated service or in cafeteria style)	0
b. are available in bowls to help oneself as desired	2
25. Kitchen	
a. is used by most residents for obtaining drinks and preparing food	2
b. is used by few residents for obtaining drinks or preparing food	0
26. Occupational or industrial training, A.T.C. school or activities off the unit on week-days are usually attended by	
a. most of the residents	2
b. few of the residents	0

27. Toilets	
a. are separate for staff and residents	0
b. are jointly used by both	2
28. Bathing	
a. is carefully supervised, involving staff presence most of the time	0
b. is regarded as a private affair	2
29. When having a bath residents use	
a. own personal items	2
b. flannels, towels, soap, brushes and combs provided by the Unit	0
30. Personal washing (excluding bed linen)	
a. is <i>done in a Central Laundry</i>	0
b. is done on the Unit with help from staff where required	2