

DEVELOPMENT OF TOOLS TO FACILITATE PARTICIPATION BY MODERATELY RETARDED PERSONS IN RESIDENTIAL EVALUATION PROCEDURES

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BACKGROUND

Tools to assist in evaluation of residential facilities for mentally retarded persons are well developed, such as the widely used Standards for Services for Developmentally Disabled Persons (1978) and the Programme Analysis Service Systems (1975). However, such tools characteristically do not incorporate systematic resident interview procedures. The current study arose from the desire to incorporate the moderately retarded person's viewpoint in a national residential evaluation exercise undertaken by the major New Zealand parent body for moderately retarded persons, the New Zealand Society for the Intellectually Handicapped. This body provides a wide range of community based residential facilities making it possible for some retarded persons living in the community to experience a variety of living conditions.

The quality of care aspects associated with general management policy as identified by Raynes, *et al.*, (1979) were selected as a key component of the evaluation. The possibility of exploring residents' ability to respond to a simple questionnaire incorporating the same key content as that used in staff interviews was raised as a first step towards the retarded person's participation in the evaluation exercise.

The aim of the study was therefore to develop a questionnaire for residents which tapped the same facets of quality of residential care as those explored through the staff interview. A basic assumption was made that residents' responses in the interview would reflect their unique views of their residential world. These views would have developed from an interplay of situational and internal/personal events (Sarason & Doris, 1979). This assumption meant the need to attend to the following methodological considerations:

- (1) The recognition of the probable important roles of individual characteristics such as extent of institutionalisation, amount of physiological damage, and cognitive ability on residents' responses.
- (2) The need to account or control for factors within the interview situation itself which may affect responses of retarded persons following work by Rosen *et al.* (1977).
- (3) The need to ensure that the methods of establishment of validity and reliability of responses should mirror the assumption of the unique and valuable nature of the retarded person's response.

DESIGN

Subjects

Subjects were selected from seven residential settings. These settings were chosen from within the largest city in New Zealand, as representative of a variety of community facilities serving the moderately retarded person. The settings were considered to differ in quality of care on the factors identified by King *et al.* (1971).

36 people were selected from these residences to form as homogeneous a group of moderately retarded persons as possible, on the criteria of an established diagnosis of moderate mental retardation, long-term attendance at facilities for the moderately retarded, and a clinical judgement that a physiological component was involved in aetiology. In 2 small residences all the moderately retarded residents were selected. In 5 residences the Intelligence Quotients of residents ranged from 30-70 and were checked by individual administration of a standardised test of intelligence.

Procedures

Two tools for obtaining residents' responses on quality of care were developed in a pilot study with six moderately retarded residents. First, a large number of items was selected from the content area designated by the parent group as significant in quality of residential care. This covered the factors of flexibility of routine, individualized treatment, personalized procedures, and social interaction with staff. The parent body wished also to include two further factors in their evaluation tool, resident involvement, and disciplinary measures. All items were discussed with the pilot study residents on a group basis, leading to a number being discarded. The remaining were modified in content on the basis of individual interview to form the final items used. Procedures for interview using the two tools were also clarified in the pilot study.

(A) Questionnaire

The 24 items of the questionnaire (Appendix I) required a Yes/No response, a response mode chosen in order to explore the difficulties in utilizing this form of response when questioning the retarded person. Items were balanced for positive and negative responding to minimize operation of an acquiescent response style. A probing procedure allowed for a direct internal check of response error (Hyman, 1955). The probing required a respondent to elaborate on a reply, giving examples of the events being questioned. The interviewer made a subjective estimate of the respondent's understanding of the question immediately subsequent to the full response (on a broad scale of 'good' 'uncertain' and 'poor'). Interviewers were required to note on the form gestures or expressions which led to the above ratings, and probing questions and responses to them were recorded verbatim. Half of the ratings were checked by a further person on the basis of this information in an attempt to increase the accuracy of the rating.

(B) Forced-choice non-verbal response measure

The second tool was a non-verbal response tool, in that it used a forced-choice response mode involving placement of pre-prepared written statements into a box of choice. No spoken response was required. (The technique was similar to that used in the Bene—Anthony Family Relations Test, 1957). Items identical to those presented in the questionnaire were written as statements rather than questions, on individual cards, and the resident was invited to place each card in a box of choice. There were six alternative boxes into which statements could be placed (or 'posted' as this measure was presented to residents as a posting game). One of the six boxes represented the intellectually handicapped person's own residential facility (the facility had been drawn by the person and the picture subsequently posted into this box). Two further boxes represented hypothetical residences, one a 'good' residence, and one a 'bad' residence. In a similar fashion, one further box represented the key staff member

in the intellectually handicapped person's residence, pre-drawn by the person and pasted onto the posting box. Two alternative hypothetical boxes depicted a 'good' staff member, and a 'bad' staff member. i.e Three choice possibilities allowed for placement of statements referring to residential place such as "This is the place where people come into your bedroom all the time without knocking." The resident could choose to place this statement in the box depicting his/her residence, or if on reflection deciding that it didn't belong there, could make a further decision concerning the assignment of such a statement to a 'good' or a 'bad' residence. Three choice possibilities allowed for placement of statements referring to perception of the key staff member in that residence e.g. "This is the person who says nasty things that make you feel like a little child" could be placed in the box depicting the respondent's own staff member. Satisfactory discrimination between all six posting boxes was developed before testing began. The interviewer noted the choice of placement made, as well as any verbal response, gesture, or other relevant behaviours by the respondent.

Two measures were administered concurrently, by the first two authors of this study. Situational variables were controlled to the extent that both interviewers were young women known only to the residents on a friendship basis. This friendship role was highlighted by a verbal description of it, time spent in developing mutual respect and trust (frequently involving sharing of a meal in the interviewer's own home) and assurances of confidentiality. During administration, the interviewers accepted all responses. No direct measure was taken of the resident's perception of the interviewer's status or role.

METHOD OF ANALYSIS

Two methods were used to explore the validity of the two interview tools:

- (1) A case study analysis investigated the sources of variance operating in responses to individual items by individual subjects using Hyman's (1955) four probable sources of error in individual responses as criteria for analysis.
- (2) A tentative statistical analysis used a multiple discriminant analysis method to explore the extent to which each tool and each item in the tool discriminated between residential settings.

The reliability of the tools was ascertained by comparing responses to similar content items on the questionnaire and forced-choice tool, allowing for a measure of stability of response across the tools. This measure was considered to be a reliability measure, in the sense that it compared responses across forms comparable in content although different in response mode (Guildford, 1956).

RESULTS

Results for the two tools are reported separately. For each tool reliability data is presented first, then validity data.

(a) Questionnaire

The stability of responses across tools reliability measure compared the items scored in a positive direction on the questionnaire with those scored in the same direction on the forced-choice measure. Eleven items scored an adequate reliability coefficient of above 80%, eight had clearly unacceptable reliability coefficients of below 70%, and five items were of borderline reliability.

The major method used to analyze the value of individual questionnaire items, or validity, was the case study method, utilizing Hyman's (1955) criteria. Two persons from

Residence A and two from Residence F were included as these residences showed considerable differences in quality of care on the observation measure. A check was made of the initial Yes/No response, as compared with the elaborated response which resulted from the probing procedure, and this internal check sought to ascertain the reason for inconsistency between the initial and elaborated responses (i.e. the source of error in responding). Item difficulty was found to be the major source of variance, related to, in order of frequency of occurrence, items containing more than one component, poor understanding of a word or concept, confusion in relating an item to either staff or other residents, and interpretation of the word 'can' as meaning competency rather than freedom. All six items which were clearly misunderstood by the case study residents were also clearly unreliable items. Other sources of variance were inability to recall information required, and inadequate experience necessary to make a sound judgement. Only minor variance could be attributed to the unwillingness of residents to respond truthfully.

A multiple discriminate analysis was tentatively used to validate this measure because it could ascertain to what extent the tool as a whole, and individual items, predicted group membership of individual settings. A good membership prediction of residences varying on an objective measure (the observation data) was considered indicative that the residents were both perceiving those differences in quality of care, and the tool was sensitively tapping these perceptions. The questionnaire predicted 80.56% of group membership in the seven residences.

The Jean Vanier style residences obtained the highest quality of care ratings from staff interview.

(b) Forced choice measure

Reliability was assessed by comparing all responses of a positive direction on this measure with those responded to in the same direction on the questionnaire measure. Fourteen items had an adequate reliability coefficient of above 80%, while only five were clearly unreliable with a reliability coefficient of below 70%.

Validity of this measure was assessed by a multiple discriminant analysis. This yielded a 77.78% prediction of group membership for the seven settings. There was little indication in the case study data that responses were distorted by the influence of interviewer and the interview situation. The statistical analysis yielded no information on the role of these variables, as they were controlled for in the groups studied.

As suggested by Sieber (1973) a crucial question in discussing appropriate tools and methods of analysis is not which measure is to be used, but which combination of approaches best allows an understanding of the complex factors operating in retarded resident's responses to questions on quality of residential care.

The tentative discriminant analysis method used in this study identified the more satisfactory discrimination of settings by the questionnaire tool as compared with the forced-choice non-verbal measure. Only six items of the questionnaire were responsible for this discrimination, a smaller number than that responsible for the discrimination by the forced-choice method.

The data on the ability of the tools to discriminate between residences indicates that for subjects in all but one setting the questionnaire was able to discriminate between settings in the same fashion as the forced-choice non-verbal measure.

The case study analysis was helpful in indicating that although a number of items on the questionnaire were meaningful to the residents, difficulty in understanding some items was still a serious problem. It is of interest that recall of relevant immediate experience related to the meaningfulness of an item to an individual, suggesting that increasing experience of residents with a variety of residential settings may reduce error variance. Requesting

residents to actually recall immediate experiences relating to an item may aid in meaningful response to an item.

This study aimed at developing a tool which could be used as part of an evaluation exercise and tap resident response in a systematic and reliable way. The revised questionnaire is therefore presented, (Appendix 1). This includes in it all items which fulfilled the criteria of being clearly meaningful to residents as indicated in the case study analysis, and being clearly reliable. Only some of these items discriminated between the settings used in this study as tentatively suggested by the multiple discriminant analysis.

This revised questionnaire attempts to avoid confusion between the tapping of events, expectancies, and preferences, (Rotter *et al.* 1972), by presenting a first part which requires reporting on events only, and a second part which is comparable in content but taps only preferences.

It is suggested that any use of this revised questionnaire should incorporate a thorough probing technique, include questions on perception of the status of the interviewer, and be used in a way which complements other measures forming the evaluation procedure.

SUMMARY

This study explored retarded residents' responses to several tools designed to evaluate quality of residential care within the conceptual framework provided by Tizard and associates. It is considered only one dimension of residential care. On the assumption that retarded persons' view residential care in a unique and multi-faceted way, it used several measures to explore responses and appropriate analytic procedures to ascertain the validity of responses. It highlighted some methodological considerations which are of importance in developing resident response tools which can be incorporated into residential evaluation procedures. Such tool development is seen as complementary to the current development of "grounded theory" concerning the meaning of the residential environment to the retarded person.

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Requests

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APPENDIX 1

QUESTIONNAIRE ITEMS — REFINED TOOL

PART 1 — OCCURRENCES/EVENTS

(A) *Flexible Routine*

1. Do you use the radio and T.V. only when the staff tell you to?
2. Do you get a drink from the kitchen when you want to?

(B) *Individualized Treatment*

3. Do you help yourself to food at the table?
4. Do you join in all the outings?

(C) *Personalized Procedure*

5. Do the staff here talk to you as if you are a child?
6. Do staff here always knock before they come into your bedroom?

(D) *Resident Involvement*

7. Do you tell a staff member when you are unhappy?
8. Do the staff here stop you from helping each other?

(E) *Appropriate Discipline*

9. Do the staff praise you for doing something better than before?
10. Do other residents here boss you about?

(F) *Social Interaction with Staff*

11. Are staff too busy to listen to you?
12. Does a staff member take you out by yourself sometimes?

PART 2 — PREFERENCES

(A) *Flexible Routine*

1. Do you want to have the staff say when you are allowed to use the radio and T.V.?
2. Would you like to be allowed to get a drink from the kitchen when you want to?

(B) *Individualized Treatment*

3. Would you like to be allowed to help yourself to food at the table?
4. Do you want staff to make you join in all the outings?

(C) *Personalized Procedures*

5. Do you want staff to talk to you as if you are a child?
6. Would you like staff to always knock before they come into your bedroom?

(D) *Resident Involvement*

7. Do you want staff here to let you tell them when you are unhappy?
8. Would you like staff here to stop you from helping each other?

(E) *Appropriate Discipline*

9. Do you want the staff here to praise you for doing something better than before?
10. Do you want other residents here to boss you about?

(F) *Social Interaction with Staff*

11. Do you want the staff here to be too busy to listen to you?
12. Would you like the staff here to take you out by yourself sometimes?