

ASSESSING MENTALLY HANDICAPPED ADULTS

DAVID FELCE and URSULA de KOCK

Health Care Evaluation Research Team,
University of Southampton.

JIM MANSELL

University of Kent at Canterbury.

JUDITH JENKINS

Winchester Health Authority.

INTRODUCTION

Social role valorization or normalisation (Wolfensberger, 1983; 1972) and its derivative evaluation tool, Program Analysis of Service Systems (Wolfensberger and Glenn, 1975) set a number of criteria for services to handicapped and other disadvantaged people. One is the notion of age-appropriateness; that services should represent the users as people of the chronological age that they are. This implies that in each different aspect of service operation — the physical setting, appearance and possessions of the service users, their activities and daily routine, opportunities for personal freedom and the exercise of basic rights — a service should avoid representing its users as significantly younger than they in fact are, or less mature or more irresponsible than other people of the same age.

Whether as a direct result of this philosophy or coincidentally, changes occurring in residential services for mentally handicapped people are consistent with a greater emphasis on age-appropriateness. For example, the use of ordinary housing to serve severely and profoundly mentally handicapped adults (Mathieson and Blunden, 1980; Mansell *et al.*, 1983a; Ward 1983) has provided homes which have fewer specialist design features evocative of young children and which include ordinary household appliances used by adults. There is a growing awareness that adult hairstyles, grooming and dress can be used to enhance the image of a person as a competent and worthy member of society, whereas childish styles may erode it. Similarly, the importance of meaningful occupation, including work, is now generally recognised (National Development Group, 1978) and there is a greater awareness of civil rights, such as the right to vote (Campaign for the Mentally Handicapped, 1977) that reflect on the adult status of the individual.

The rhythm of life and the activities pursued in a residential setting also influence the extent to which individuals are viewed as adult. Some sensitivity to the more obvious issues is already apparent. For example, services which through their own organisational requirements impose times of going to bed or of having meals which are considerably earlier than those chosen by other people of similar age are thought to be of poor quality. However, it is not only the timing of activities that needs scrutiny in this respect but also their content. For the most severely or profoundly mentally handicapped people in particular, attempts to provide constructive occupation (if any attempt is made at all) usually involve some form of diversion employing pre-school nursery toys and educational materials. With the development of 'educational play' for small children, the growth of developmental psychology and concepts such as 'mental age', services for mentally handicapped people have indiscriminately adopted not only the developmental approach to learning but the curriculum and resources of the nursery and primary school as well.

The purpose of this paper is to propose a critical re-evaluation of this strategy, particularly where mentally handicapped adults are concerned. We suggest that the child's curriculum is inappropriate and that it should be possible to use the activities of non-handicapped people as the basis for learning and for occupation. This is not to ignore the need to learn simple motor, cognitive and discrimination skills to enable participation in more complex activities: what is proposed is the translation of these skills from the traditional applications using toys to the natural adult world.

Adult household activity

Mentally handicapped people in residential care often experience enforced leisure because, in a sense, the organisational and staffing arrangements take away all opportunities to participate in the range of daily living activities that ordinarily occupy the householder. Concern at the characteristically low levels of activity in residential settings has led to staff training to increase client use of recreational materials during short periods of organised activity (Porterfield *et al.* 1980; Walter, 1978; Coles and Blunden, 1981). Our own attempt to organise similar periods (Mansell *et al.* 1982) led us to question the value and usefulness of such recreational activities as the main occupation for people during the day. It might be argued that these activities should be chosen either because they are simple enough for very handicapped people to do or because they are intrinsically rewarding in that they are enjoyable, fun and make no great demands on the person doing them. However, the argument that toys are the materials of choice because they are simple to use confuses simplicity with childishness. There are many activities or parts of activities in adult life which are simple; and as we concluded in our own study, many toys require a level of symbolic competence not possessed by people with severe or profound degrees of mental handicap. Moreover, when collecting many hours of observational data in the study, we were struck not by the eagerness with which people approached the recreational materials but rather by their lack of interest.

There are further arguments against using recreation as the principal activity. Firstly, it is difficult to provide as much variety as anyone might need, whether or not they had shortened attention span and limited skills. If a person can already do the task (i.e. it is within their existing repertoire and they are not being taught) then it is often completed quickly and even a large stock of materials cannot prevent the same activities being presented to the client again and again in the course of the day or week. Secondly, far from being more interesting than ordinary activities, an exclusive focus on recreation seems to pose a number of problems of motivation. It is open to the influence of social pressures (either directly experienced by users or mediated by staff perceptions of the worth of the activity and the effort it merits) that it is trivial, time-filling and meaningless; does it matter how fast people complete jigsaws or stack blocks? It may also be that recreational activities, since they are not linked into the sequence of essential daily activities, depend more on extrinsic social reinforcers than on intrinsic sources such as achievement, control and completion.

In the residential situation, the age-appropriate sources of activity involve those housekeeping tasks which the lives of the service users generate; the need to shop, prepare food, cook, lay the table, wash up, tidy, clean, launder, decorate and garden. Our experience in setting up a residential service designed to use these activities as the principal source of opportunities for severely or profoundly mentally handicapped people (Mansell, *et al.*, 1983a) has shown that household activities can be structured to allow their participation (Mansell *et al.* 1984, Felce *et al.* 1984a). Although it is difficult to disentangle the effect of change in materials from other features of the service, comparative evaluation with traditional hospitals does show higher levels of purposeful activity in the houses (Felce, *et al.* in press).

The educational curriculum and teaching process

Teaching and the support of continuing development of the individual also has an important place in a residential service (e.g. National Development Group, 1978). The idea of age-appropriateness has an equal impact on the educational curriculum. It serves to provide a reminder that the objective of the educational process is to equip people with the skills relevant to an independent adult lifestyle and the pursuits and responsibilities of that age group. This is not to ignore the preparatory stages of development but it is to question the futility of a lifetime spent preparing but never reaching the final target.

It might be argued that toys and leisure materials have some special place in the educational process; that they have a particular role in promoting learning. The comment already made about confusing simplicity with the age-image of the materials is relevant here. Moreover, it is possible to define the teaching process in a way which distinguishes method from content and there is nothing to suggest that the method can be only applied to childish content. The National Development Group (1978) cite various principles of teaching including (a) a behavioural assessment to establish the person's entry repertoire, (b) the setting of a precise teaching objective, (c) constructing a teaching programme involving a series of separate steps, (d) the inclusion in the programme of a method of reinforcing skill acquisition, (e) the inclusion in the programme of a method of providing corrective instruction and (f) the opportunity to use the acquired skill in the everyday environment. All these steps can be carried out with adult tasks and materials.

The assumption that toys are important because play is the preferred medium of learning may be relevant to children (although even here children seem to spend time trying to involve themselves in adult activities) but it seems questionable for mentally handicapped adults. Indeed, given the limited rate of learning by a person with mental handicap the most efficient teaching strategy may be to teach directly on important life activities — to eschew attempts to repeat the idealised steps a non-handicapped child is supposed to pass through in favour of a more pragmatic concentration on the areas which will make the most difference to the person's lifestyle. Further, insofar as recreational activities entail a greater reliance on social reinforcers to maintain client engagement they may be less efficient at delivering contingent reinforcement than adult ('real') activities which lead to practical consequences. They may therefore entail weaker instructional processes and pose greater problems of generalisation. Finally, the kind of individual educational planning and intervention process required for severely mentally handicapped people is resource-intensive. It is therefore important that it is used to best effect and that staff required to invest time and effort in it view it as an important activity worth doing. The credibility gained among staff by teaching adults practical usable skills directly may be a considerable asset to the continuation of teaching.

A goal-setting checklist of adult activity

If the educational curriculum in the residential setting is to be geared to ordinary household activities rather than to leisure and recreation it follows that the assessment of a person's abilities and the choice of teaching goals could most usefully reflect this fact. Typically, however, behavioural inventories reflect childish activities and developmental stages. We have attempted to rectify this deficit in our own precision-teaching model, the Berewecke skill-teaching system, (Mansell *et al.* 1983b) by compiling an age-appropriate checklist for use with severely and profoundly mentally handicapped adults. It was developed from the earlier Checklist published in the Berewecke System (Jenkins *et al.*, 1983) which remains relevant for children. In a similar way to the original, the Checklist is designed not as a formal assessment but as a guide to establishing the individual's current repertoire

and to selecting relevant skills to be acquired.

The content of the age-appropriate checklist (Felce *et al.*, 1984b) is outlined in Table 1. The activities assessed are drawn from three main areas; the individual's own self-care, household activities and social relations. In addition, three other groups of skills (receptive and expressive language abilities, basic numeracy and component skills — a range of motor and cognitive skills involved in making up other activities) are included.

Table 1
Content of the Age-appropriate checklist

<i>Self-care</i>	<i>Household</i>	<i>Socialisation</i>
Eating/drinking	Mealtime activities	
Washing	Kitchen tasks	
Undressing/dressing	Clothes care	
Toileting	Domestic tasks	
Grooming		
<i>Receptive and Expressive Language</i>		<i>Component Skills</i>
Identifying named items		Grasping and releasing
Comprehension		Fine manipulation
Use of language : general		Gross manipulation
: nouns		Body control
: verbs		Sport
: other		Cognitive
	<i>Number</i>	

The sections on component skills include the same range of items as in the previous checklist but each item has been translated into an adult context. Thus, they are not only directly relevant activities themselves but, insofar as they may be taught as pre-requisite skills to more complex goals, they also serve to show how such goals can be broken down without using childish materials or contexts. Examples of how age-appropriate items are used in the checklist are given in Tables 2, 3 and 4.

Table 2
Comparison of child-oriented checklist and adult-oriented checklist
Examples of: Grasping and releasing skills

<i>Skill</i>	<i>Childish assessment</i>	<i>Adult assesement</i>
Grasps, picks up takes object	Assessed by using toy	Assessed by using, for example, apple, glass of drink, plate
Pincer grip	Assessed by using crayon	Assessed by using toothbrush in holder or mug
Pushes object	Assessed by using toy car	Assessed by using cloth to wipe surface
Removes objects from/ places objects in container	Assessed by using four buttons in a box	Assessed by using adult contents: <ul style="list-style-type: none"> a. small tin/jar/ packet in/out of cupboard b. cutlery in/out of drawer c. biscuit out of tin; empty packet into flip-top bin d. chocolate from box of chocolates; tea- bag into pot e. coin in/out of pocket/purse

Table 3
Comparison of child-oriented checklist and adult-oriented checklist
Examples of: Fine manipulation

<i>Skill</i>	<i>Childish assesement</i>	<i>Adult assesement</i>
Alignment, posting objects into slots	Pull pegs from pegboard large — small	Take : a. newspaper from letterbox b. milk bottle from fridge door c. toothbrush from holder
	Puts pegs into pegboard large — small	Puts : a. letter in postbox b. milk bottle into fridge door c. plate into plate rack d. coin in vending machine e. coin in payphone f. cassette into player g. toggle into button- hole h. belt through trouser loop i. key in door j. shirt button through hole k. shoelace through eye l. thread through needle
Nests objects	Assessed by childish nesting toy	Stacks bowls of different sizes
Unscrews/screws	Assessed using screw toy	Unscrew coffee jar Unscrew toothpaste tube Puts lid on saucepan Screws a lid on coffee jar Screws a lid on tooth- paste tube
Stacking	Builds 6-block tower with children's blocks	Stacks 2 tins one on top of other Stacks 3 tins in pyramid

Table 4
Comparison of child-oriented and adult-oriented checklist
Example of cognitive skills

<i>Skill</i>	<i>Childish assesement</i>	<i>Adult assesement</i>
Matching objects	Assessed using toys e.g. ball, doll, book	Assessed with tin, jar and packet when unpacking shopping: puts tin with tins, jar with jars, packet with packets
Matching objects by picture	Assessed using cards with simple pictures	Assessed using cards with different labels
Sort by colour	Assessed using coloured blocks	Assessed using bed- linen of different colours

The new checklist was first conceived as matching the original item-for-item. However, in following the rule that the checklist should assess behaviours directly relevant to the everyday life of adults, while recognising that people would be severely or profoundly mentally handicapped, a number of strategic differences became apparent. The first of these concerned language (examples of two sections of the language assesement are given in Table 5). If a mentally handicapped adult does not make sounds, the strategy of following the developmental sequence of eliciting babbling and shaping more complex vocalisations, which might be the first choice with children, is less likely. Unless the circumstances suggest that the person can readily be introduced to this sequence, the alternative of teaching a sign language may be a more viable investment of teaching effort. Thus, the checklist does not include an assessment of the early development of speech. Similarly, for a person who does vocalise, a developmental sequence strategy may be no more attractive than direct shaping of sound formation to approximate useful whole words. Thus the assesement of expressive and receptive language includes a vocabulary list with few developmental milestones.

In a similar way, consideration of the final skill level that can be reached influenced the construction of the section on pre-academic skills. If an adult is still functioning as very severely or profoundly mentally handicapped it seems unlikely that he will ever be able to read and write fluently, or to manipulate numbers symbolically. But, in the adult world, the only real applications of these skills require fluency; even the need to use a social-sight vocabulary ('look and say') is very limited since in almost all conceivable applications there are other environmental cues than the word alone. So, content which should be represented in a checklist for children is not required in a checklist for adults.

The dual criteria of age-appropriateness and only teaching skills which will be used in the real environment also influences items relating to the arts. Broadly speaking, these areas (e.g. painting and music) require a certain standard of competence to be done by adults. Even if only pursued as a hobby, the gap between the standard of performance achieved as children and that needed to continue with the activity as worthwhile or even acceptable in adult life most people who commenced learning such skills in childhood

to give up in later life. Thus it may be that mentally handicapped people are so extensively occupied in painting and music typical of the primary school because staff cannot think of anything else to do rather than because these activities are important in the individual's lifestyle.

Table 5
Example pages from the language sections

				<i>IDENTIFYING NAMED ITEMS</i>							
<i>Food/drink</i>				<i>Community</i>							
Potatoes	<input type="checkbox"/>	Porridge	<input type="checkbox"/>	Orange	<input type="checkbox"/>	Pastry	<input type="checkbox"/>	Shop	<input type="checkbox"/>	Cat	<input type="checkbox"/>
Chips	<input type="checkbox"/>	Cereals	<input type="checkbox"/>	Banana	<input type="checkbox"/>	Flour	<input type="checkbox"/>	Car	<input type="checkbox"/>	Post Box	<input type="checkbox"/>
Carrots	<input type="checkbox"/>	Toast	<input type="checkbox"/>	Pear	<input type="checkbox"/>			Bus	<input type="checkbox"/>	Telephone	<input type="checkbox"/>
Peas	<input type="checkbox"/>	Bread	<input type="checkbox"/>	Sugar	<input type="checkbox"/>			Road	<input type="checkbox"/>	Box	<input type="checkbox"/>
Cabbage	<input type="checkbox"/>	Sandwich	<input type="checkbox"/>	Drink	<input type="checkbox"/>			Pavement	<input type="checkbox"/>		
Parsnip	<input type="checkbox"/>	Jam	<input type="checkbox"/>	Water	<input type="checkbox"/>			Tree	<input type="checkbox"/>		
Meat	<input type="checkbox"/>	Marmalade	<input type="checkbox"/>	Tea	<input type="checkbox"/>			Park	<input type="checkbox"/>		
Fish	<input type="checkbox"/>	Butter	<input type="checkbox"/>	Coffee	<input type="checkbox"/>			Grass	<input type="checkbox"/>		
Egg	<input type="checkbox"/>	Salt	<input type="checkbox"/>	Sweet	<input type="checkbox"/>			Cinema	<input type="checkbox"/>		
Bacon	<input type="checkbox"/>	Pepper	<input type="checkbox"/>	Wine	<input type="checkbox"/>			Pub	<input type="checkbox"/>		
Sausage	<input type="checkbox"/>	Pickle	<input type="checkbox"/>	Beer	<input type="checkbox"/>			Cafe	<input type="checkbox"/>		
Beans	<input type="checkbox"/>	Sauce	<input type="checkbox"/>	Cider	<input type="checkbox"/>			Bakers	<input type="checkbox"/>		
Corn	<input type="checkbox"/>	Cake	<input type="checkbox"/>	Squash	<input type="checkbox"/>			Butchers	<input type="checkbox"/>		
Tomato	<input type="checkbox"/>	Biscuit	<input type="checkbox"/>	Lemonade	<input type="checkbox"/>			Post Office	<input type="checkbox"/>		
Cheese	<input type="checkbox"/>	Pudding	<input type="checkbox"/>	Crisps	<input type="checkbox"/>			Bank	<input type="checkbox"/>		
Milk	<input type="checkbox"/>	Apple	<input type="checkbox"/>	Nuts	<input type="checkbox"/>			Dog	<input type="checkbox"/>		

<i>USE OF LANGUAGE: OTHER</i>											
<i>Colour</i>	<i>Number</i>	<i>Size/shape</i>	<i>Comparisons</i>	<i>Prepositions</i>	<i>Time</i>						
Red	<input type="checkbox"/>	One	<input type="checkbox"/>	Big	<input type="checkbox"/>	Wet	<input type="checkbox"/>	In	<input type="checkbox"/>	Morning	<input type="checkbox"/>
Blue	<input type="checkbox"/>	Two	<input type="checkbox"/>	Little	<input type="checkbox"/>	Dry	<input type="checkbox"/>	On	<input type="checkbox"/>	Afternoon	<input type="checkbox"/>
Yellow	<input type="checkbox"/>	Three	<input type="checkbox"/>	Large	<input type="checkbox"/>	Hot	<input type="checkbox"/>	Under	<input type="checkbox"/>	Evening	<input type="checkbox"/>
Green	<input type="checkbox"/>	Four	<input type="checkbox"/>	Small	<input type="checkbox"/>	Cold	<input type="checkbox"/>	Behind	<input type="checkbox"/>	Night	<input type="checkbox"/>
Brown	<input type="checkbox"/>	Five	<input type="checkbox"/>	Round	<input type="checkbox"/>	Clean	<input type="checkbox"/>	Next to	<input type="checkbox"/>	Tomorrow	<input type="checkbox"/>
Black	<input type="checkbox"/>		<input type="checkbox"/>	Square	<input type="checkbox"/>	Dirty	<input type="checkbox"/>	In front	<input type="checkbox"/>	Today	<input type="checkbox"/>
White	<input type="checkbox"/>		<input type="checkbox"/>	Short	<input type="checkbox"/>	Top	<input type="checkbox"/>	Above	<input type="checkbox"/>	Yesterday	<input type="checkbox"/>
Grey	<input type="checkbox"/>		<input type="checkbox"/>	Long	<input type="checkbox"/>	Bottom	<input type="checkbox"/>		<input type="checkbox"/>	Before	<input type="checkbox"/>
Orange	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>	After	<input type="checkbox"/>
										Now	<input type="checkbox"/>

Finally, one of the effects of translating the original checklist into its new form is that, as well as finding that some areas are thinned other areas can be considerably expanded. Thus for example in all the practical sections on housework activities or component skills it is easy to find many relevant applications where only one or two based on the use of toys have traditionally been employed. Partly this reflects the lack of variety that toys provide, and partly our own history of viewing a single item in a psychological test as standing for a general level of functioning. Since one of the main purposes of this checklist is to serve as a source of ideas for teaching goals, a longer and more diverse list is entirely appropriate.

Implications of a new assesment curriculum

The change in the assessment checklist follows a change in our own perceptions of the purpose of teaching in residential settings and a recognition of what can be achieved in environments designed to support involvement in adult activity. Paradoxically, one of the implications of a switch to this kind of curriculum is that many settings will need to modify their operation so that opportunities exist to learn and then do the activities which the checklist assesses. Although all the items in the checklist relate to everyday activity in an ordinary home, many settings will not have the materials and opportunities required (and it may be as difficult to get them as it is to get a full range of the toys other assessments need).

Similarly, this model of operation makes new demands on staff in terms of their roles and training. It is essential that no-one believes that it is their job to do household activities while excluding service users; that, on the contrary, staff are appointed on the understanding that their task is to assist the people they serve to do the activities to the greatest possible extent. This also requires staff training on how to conceptualise everyday activities as sequences of single behavioural components which even very handicapped people can do, so that staff can judge their level of assistance to promote the maximum independence (i.e. use of skills) of the handicapped person.

Although adoption of a new curriculum will pose practical problems for many environments in terms of staff training and availability of opportunities and materials, we suggest that this is a fruitful direction for further work. Given the very great difficulty in achieving reasonable participation in activity when using toys to occupy mentally handicapped people, any alternative should be seriously explored for its potential. Whether or not one accepts the rationales about the effect of the childish image on staff and user perceptions of the tasks, or the as yet relatively unexplored questions concerning the intrinsic sources of motivation in different activities, the variety and relevance of adult household tasks should make them strong contenders for consideration.

Acknowledgements

This manuscript was prepared under D.H.S.S. Grant No. 0708.

References

- CAMPAIGN FOR THE MENTALLY HANDICAPPED (1977). Electoral registration and voting residents in mental handicaps hospitals, London: CMH.
- COLES, E. and BLUNDEN, R. (1981). Maintaining new procedures using feedback to staff, a hierarchical reporting system and a multi-disciplinary management group. *Journal of Organisational Behaviour Management* 3, 19-33.
- FELCE, D., DE KOCK, U., and REPP, A. C. (in press). An ecological comparison of small home and institutional settings: I Provision of opportunities by staff and client engagement in activity. *Applied research in mental retardation*.
- FELCE, D., MANSELL, J., DE KOCK, U., TOOGOOD, S. and JENKINS, J. (1984a). Housing for severely and profoundly mentally handicapped adults. *Hospital and Health Service Review*, 80, 170-174.

- FELCE, D., JENKINS, J., DE KOCK, U., and MANSELL, J. (1984b). *The Berewecke Skill-teaching System -- Goal-setting checklist for adults*. Health Care Evaluation Research Team, University of Southampton.
- JENKINS, J., FELCE, D. and MANSELL, J. (1983). *The Berewecke skill-teaching system: Assessment checklist*. Windsor: National Foundation for Educational Research/Nelson Publishing Co.
- MANSELL, J., FELCE, D., JENKINS, J., DE KOCK, U. and TOOGOOD, S. (1983a) A Wessex home from home. *Nursing Times* Aug. 3, 51-56.
- MANSELL, J., FELCE, D., FLIGHT, C. and JENKINS, J., (1983b). *The Berewecke skill-teaching system: programme-writers handbook*. Windsor: National Foundation for Educational Research/Nelson Publishing Co.
- MANSELL, J., FELCE, D., DE KOCK, U. and JENKINS, J. (1982). Increasing purposeful activity of severely and profoundly mentally handicapped adults. *Behaviour Research and Therapy*, 20 593-604.
- MANSELL, J., JENKINS, J., FELCE, D. and DE KOCK, U. (1984). Measuring the activity of severely and profoundly mentally handicapped adults in ordinary housing. *Behaviour Research and Therapy*, 22 1, 23-29.
- MATHIESON, S. and BLUNDEN, R. (1980) Nimrod is piloting a course towards a community life. *Health and Social Service Journal*, 90 Jan 25, 122-124.
- NATIONAL DEVELOPMENT GROUP (1978). *Helping mentally handicapped people in hospital*. London: Dept. of Health and Social Security.
- PORTERFIELD, J., BLUNDEN, R., and BLEWITT, E. (1980) Improving environments for profoundly handicapped adults: using prompts and social attention to maintain high group engagement. *Behaviour Modification*, 4 225-241.
- WALTER, A. (1978). Intervention strategies with a group of profoundly mentally handicapped adults. Unpublished Diploma Thesis.
- WARD, L. (1983). Mental handicap: an ordinary life. *Community Care*, 10 Nov.
- WOLFENBERGER, W. (1972). *Normalisation: the principle of normalisation in human services*. Toronto, National Institute of Mental Retardation.
- WOLFENBERGER, W. (1983). Social role valorization: a proposed new term for the principle of normalisation *Mental Retardation*, 21 6, 234-239.
- WOLFENBERGER, W. and GLENN, L. (1975). *Program Analysis of Service Systems*. Toronto: National Institute on Mental Retardation.