

II. AN EPIDEMIOLOGICAL STUDY OF MENTAL RETARDATION AND THE P-A-C

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INTRODUCTION

The Mental Health Research Institute of Victoria, Australia, carried out recently a study of the 'Needs of the Mentally Retarded in the Community', (Krupinski *et al.*, 1981). A stratified sample of 718 families was drawn from 5770 mentally retarded known to the Victorian Mental Retardation Services. A comprehensive semi-structured interview schedule was devised to record information on health, physical disabilities, educational achievements and social functioning of subjects. Details of social and familial background, relationships with other family members, and effects upon the family were also recorded. Information on the type of care and use of counselling and welfare services, since retardation was diagnosed, was noted along with the family's expressed current and future needs in respect of the retarded member. The interviews were carried out by qualified social workers and senior social work students specially trained for that task. Successful interviews were obtained for 529 subjects, the response rate being 73.7% (further details see page 31).

An important part of a community survey of mentally retarded is the assessment of their development and social performance. The recorded diagnosis of the level of retardation cannot be regarded as very reliable, as it was often made a long time ago, and had been, in a number of cases, based on clinical judgement only. To measure the IQ of every subject in an interview situation is not practical, especially when one relies on non-psychologically trained interviewers. More importantly, social competence is a better indicator of the needs of the mentally retarded than their intelligence quotient.

In a previous study (Krupinski *et al.*, 1973) the Vineland Social Maturity Scale (Doll, 1965) was used to measure the social potential of individual subjects. The value of this scale is its ability to express the social potential of the subject in terms of an age equivalent of the total score (Social Age) and in the calculation of a Social Quotient by relating the social age to the chronological age. It can also be subdivided into specific areas to determine discrepancies in the total development of the subject. The major limitation of the scale is that it can be administered only by psychologically trained interviewers.

Because of this, we selected the Progress Assessment Charts (P-A-C) developed by H. C. Gunzburg (1973 and 1974) to measure the social competence of our subjects. The individual items, included in the range of the five charts, cover a wide variety of social skills and performances that have been selected on the basis of their relevance to everyday life and the extent to which they may be attained by mentally retarded persons. They provide a more comprehensive list of social skills than other tests measuring social age, partly due to the fact that they have been designed specifically for individual assessment of retarded persons within an educational programme and partly because they allow for the uneven development of social competence that is typical of the mentally retarded subject. Tests specifically designed for non-retarded children often rely on few key skills from which a general level of ability may be inferred — due to the relatively even and predictable pattern of development of normal children.

The Progress Assessment Charts are currently in wide use in all parts of the world to measure the developmental progress of individual subjects. Mostly, they are used as clinical instruments, providing on-going measures of development and enabling the adjustment of training programme to meet the particular needs of the individual.

In our study we have used the Progress Assessment Charts as an epidemiological tool in order to determine the levels of social competence of a large group of subjects rather than as a measure of individual development for which it was originally designed. To do this, it has been necessary to make a number of modifications to the method of assessment to adapt it to our purpose.

The five P-A-C forms have been designed for specific groups of mentally retarded selected in terms of their chronological age and attained skills. The Primary P-A-C form aims at mentally retarded children of up to seven years (and sometime older) and covers behaviours appropriate for normal development up to three years of age. The P-A-C-1 chart may be used for retarded children of between six and sixteen years as well as for certain groups of older retarded persons. It is relevant for the assessment of skills and behaviours appropriate for normal development up to eight years of age. The M/P-A-C-1 is an adaption of the P-A-C-1 for use with Down's Syndrome children of six to fifteen years. It contains the same items as the P-A-C-1 form, but presents them in an order more appropriate to the specific diagnostic group. The A/P-A-C 1 form is an extension of the P-A-C-1 and contains additional social skills. It is suitable for mentally retarded children of advanced school age. Finally the P-A-C-2 chart has been specifically designed for adolescent and adult mentally retarded persons. Gunzburg developed for each form a Social Competence Index (SCI), in order to compare the development of the individual with that of the group for which the form was designed. Finally, the individual Progress Assessment Charts monitor the development of specific skills of the subject in the four major areas; self-help, communication, socialisation and occupation.

OBJECTIVES AND METHOD

In our study we used the P-A-C with different objectives. Firstly, we aimed at a comprehensive scale of development, which would cover the whole range of mental retardation. Secondly, we wanted to relate the recorded level of social competence with that expected for the particular chronological age. And finally, we felt it important to determine the evenness or otherwise of development at specific levels of social competence.

Of a total of 504 subjects where personal interviews with parents or guardians were conducted, P-A-C assessments were made for 475 individuals (94.2%). Their age distribution was as follows:

0- 5 years	47
6-10 years	127
11-16 years	109
17-29 years	131
30+ years	16

In pursuing our first aim we were not able to develop a single continuous inventory of items ranging from infant to adult behaviours. This was due to inconsistency between different forms in assigning skill levels for specific behaviours, and to the unsystematic overlapping of items between adjacent forms. Therefore in constructing a Modified Scale of Social Competence we could use only a selection of items from the five forms. The original sixteen levels in the five forms of the P-A-C have been reduced to a total of thirteen levels due to the overlaps between forms. This overlapping occurred at Levels 5 and 6, and Levels 10 and 11 of the Modified Scale (Table 1). For each of the four areas (self-help, communication, socialisation and occupation) at least three items appropriate to each of the thirteen levels were included in the Modified Scale. Items regarded as ambiguous or open to misinterpretation by interviewers were rejected from the construct. Changes in ordering of some items were made when the number of subjects passing a particular item indicated strongly that the ranking on the original forms was incorrect for our sample or where the rank ordering of a specific behaviour differed from one P-A-C form to another. Interviewers

selected the P-A-C form on the basis of the subject's general level of competence, using the chronological age as only a secondary factor in form selection. Thus, a ten year old, with a level of competence equivalent to that of a very young normal child, was assessed with the Primary Form (P-P-A-C) rather than the P-A-C-1, which would have been the appropriate form using the selection criteria of the author of the P-A-C method. In a number of cases, interviewers had difficulty in selecting only one form for the assessment as the individual's range of skills overlapped two forms. In these cases, the assessment was made using both forms. One-third of all assessments were made using the P-P-A-C alone. Multiple forms were completed for one in eleven (9.1%) of subjects.

Table 1

Ideal Relationship between the Sixteen Levels of Gunzburg's P-A-C and the Thirteen Levels of the Modified Scale.

Modified Scale Levels	Age Equivalent	P-A-C Form Levels		
		P-P-A-C (Blue)	P-A-C-1 (White)	P-A-C-2 (Yellow)
1	Three Months	a		
2	Six months	b		
3	Nine Months	c		
4	Two years	d		
5	Three years	e	A	
6	Four and a half years	f	B	
7	Six years		C	
8	Seven years		D	
9	Eight years		E	
10	Nine years		F	
11	Ten years		G	X
12	Eleven years			Y
13	Twelve years and over			Z

To determine each subject's level on the scale, the number of items which were ticked as being performed at each of the thirteen levels was checked. For each area, any level where fifty per cent or more of the items were checked was considered as being attained by the subject. In cases where the subject failed to pass levels below the highest level attained an averaging procedure was used. The final level assigned in these situations was the average of the 'minimum' and 'maximum' levels. The 'minimum' level was taken as the highest level attained before any individual items in the scale were missed. The 'maximum' level was the highest level in which any item had been checked as being performed — regardless of how many previous items had been missed. The average of these two level numbers determined the final level for the subject. This procedure was considered to be the most reliable measure of competence as the 'minimum' level item could be an under-estimation and the 'maximum' item level an over-estimation. In practice, the correlation between the two was high. The overall level of social competence has been calculated as the average of the levels reached in the four major areas.

In order to take account of both the subject's assessed level of social competence, as measured on the Modified Scale, and his/her age, an Index of Social Competition was devised. Items included in each of the thirteen levels of the Modified Scale were examined and, for each level, an age was assigned that represented the age at which a non-retarded child might be expected to perform the skills involved (see Table 1). Although some skills and

behaviours are clearly identifiable with specific periods of normal child development, it is acknowledged that this assignment of age equivalents of normal development is at best a somewhat crude estimation.

The Index for each subject was determined by assessing the global level of performance on the Modified Scale taking the age equivalent of normal development for the level, and expressing it as a percentage of the subject's chronological age. Thus, a child of ten years with an assessment at Level 5 was considered to have an Index of Social Competence of thirty-three per cent.

Because the maximum age equivalent of normal development was twelve years, it was necessary to set an arbitrary maximum age for adolescent and adult subjects to avoid their Index scores being decreased inappropriately due to their age. For the calculation of the Index, all persons over fourteen years were taken as being fifteen years old.

Two methods were used to determine the unevenness of the development of social competence. Firstly, the levels reached in each of the four areas of social competence (self-help, communication, socialisation and occupation) were compared. Secondly, the whole sample was divided into six groups in terms of the overall level of social competence (1-2, 3-4, 5-6, 7-8, 9-10 and 11-13). For each of the six groups, the percentage of subjects who had mastered each specific item in the relevant P-A-C form/s was calculated. The results of this analysis are presented graphically using modified reproductions of the appropriate P-A-C forms. (see Fig. 1 to 3).

RESULTS

Table 2 provides information on the attained overall level of social competence as well as for the four chart areas. At least sixty-nine per cent of subjects attained Level 4 on both their overall rating and the rating on each of the four sub-scales. One-third attained Level 9 on each of the five measures, whilst sixteen per cent reached Level 11 on the overall rating. Only ten persons (2.1%) attained an overall rating at the maximum Level 13, although higher numbers reached that level in each of the four areas of competence.

Table 2

Assessed Scores on Modified Scale of Social Competence (numbers; Cumulative percentages)

<i>Modified Scale Level</i>	<i>Progress Assessment Chart Area</i>									
	<i>Self-Help</i>		<i>Communication</i>		<i>Socialisation</i>		<i>Occupation</i>		<i>Overall Assessment</i>	
1	65	100.0	61	100.0	52	100.0	63	100.0	64	100.0
2	24	86.3	58	87.2	38	98.1	40	86.7	47	86.5
3	21	81.3	23	74.9	39	81.1	29	78.3	35	76.6
4	45	76.8	43	70.1	22	72.8	40	72.2	36	69.3
5	36	67.4	54	61.1	27	68.2	25	63.8	32	61.7
6	34	59.8	40	49.7	51	62.5	41	58.5	25	54.9
7	27	52.6	19	41.3	19	51.8	17	49.9	45	49.7
8	20	46.9	26	37.3	43	47.8	26	46.3	22	40.2
9	29	42.7	38	31.8	22	38.7	20	40.8	39	35.6
10	71	36.6	43	23.8	75	34.1	70	36.6	53	27.4
11	35	21.7	25	14.7	41	18.3	46	21.9	36	16.2
12	27	14.3	27	9.5	14	9.7	23	12.2	31	8.6
13	41	8.6	18	3.8	32	6.7	35	7.4	10	2.1

The calculation of the Index of Social Competence (Table 3) showed that one in six of all subjects were functioning at a level equal to seventy per cent (or more) of their chronological age. The relation of the level of mental retardation to the Index of Social Competence was much stronger than it was to the assessed level of social competence — the latter being unrelated to age.

Table 3
Level of Mental Retardation by Social Competence

<i>SOCIAL COMPETENCE</i>	<i>Level of Retardation</i>			
	<i>Borderline/Mild (IQ: 52-85) (N=88) %</i>	<i>Moderate (IQ: 36-51) (N=192) %</i>	<i>Severe (IQ: 20-35) (N=86) %</i>	<i>Profound (IQ: 20) (N=59) %</i>
(Modified Scale				
1-2	3.4	8.4	39.4	79.7
3-6	7.9	26.6	52.3	15.3
7-10	36.4	53.6	7.1	5.0
11-13	52.3	11.4	1.2	0.0
Index				
Less than 20%	1.1	16.1	67.4	94.9
20%<35%	5.7	7.8	19.8	1.7
35%<50%	8.0	24.0	8.1	1.7
50%<70%	44.3	36.5	4.7	1.7
70% or more	40.9	15.6	0.0	0.0

Already the data presented in Table 2 indicate the unevenness in the development of social competence. However, this became even more apparent when the P-A-C charts were prepared for the six groups of social competence¹.

The severely impaired groups were lagging behind especially in the area of communication. Thus in the level 3-4 group (Figure 1) less than half of the subjects reached that level in the 'communication from' area, whilst more than half passed levels 5 and 6 items in the 'self-help' area. In the moderately impaired group (levels 7-8) the attained skills in 'occupation' and 'socialisation' (especially play activities) were much higher than expected, whilst the reverse was true for 'communication' (Figure 2). Finally, in the mildly impaired group (Levels 11-13) the uneven attainment of skills was apparent even within specific areas, such as 'occupation' or 'socialisation'. Whilst the majority of subjects mastered leisure, occupation and manual activities, less than one-third were able to keep time, work speedily and reliably, or look after tools. Of the various 'socialisation' skills, items included under 'home assistance', 'social graces' and 'shopping activities' were attained at higher levels than items referring to financial dealings or social initiative (Figure 3.)

The Progress Assessment Charts enable the user to identify specific skills if the individual's level of achievement is markedly different — higher or lower — than might be expected on the basis of the overall level of social competence. Thus, in the 'self-help' area — generally well attained — only 10-29% of subjects in the severely impaired group (Figure 1) were able to 'prepare edible food by peeling or unwrapping', whilst 50-69% could 'play in company with others — a skill considered appropriate to a higher level of

¹ Of these only three are presented

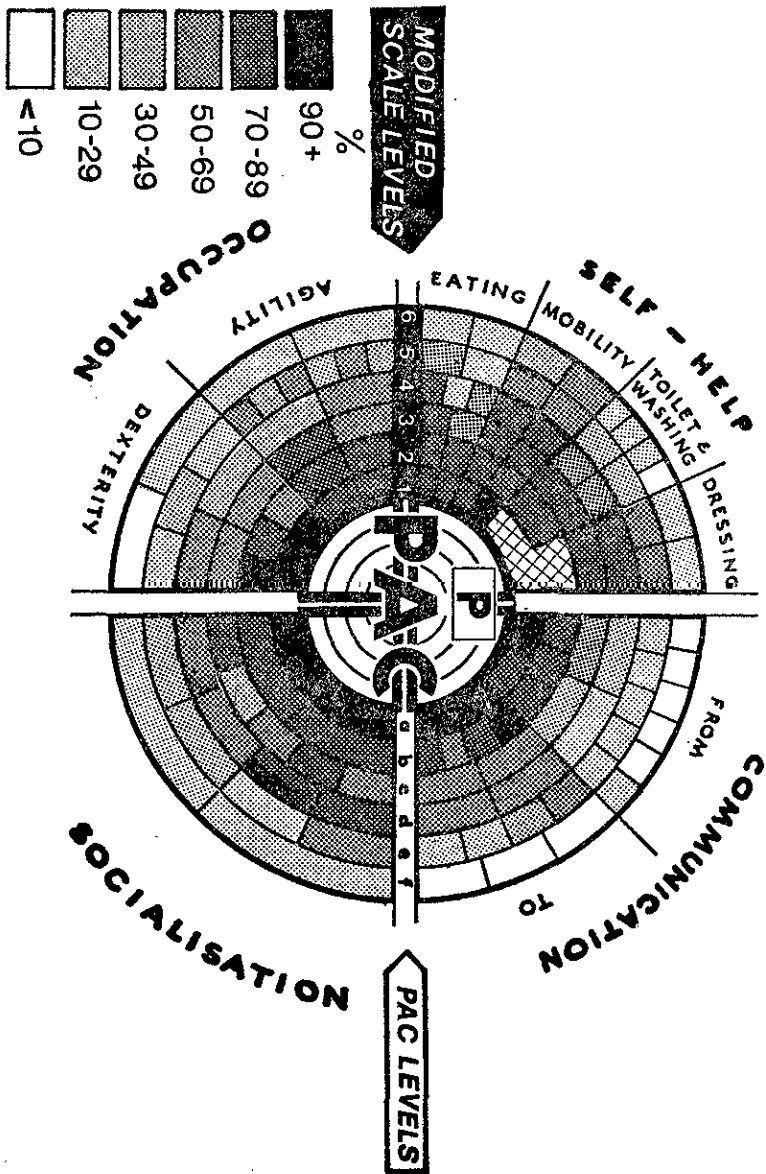


Figure 1 Percentage of the severely impaired group (Modified Scale Levels 3-4) attaining specific items on P-P-A-C Form

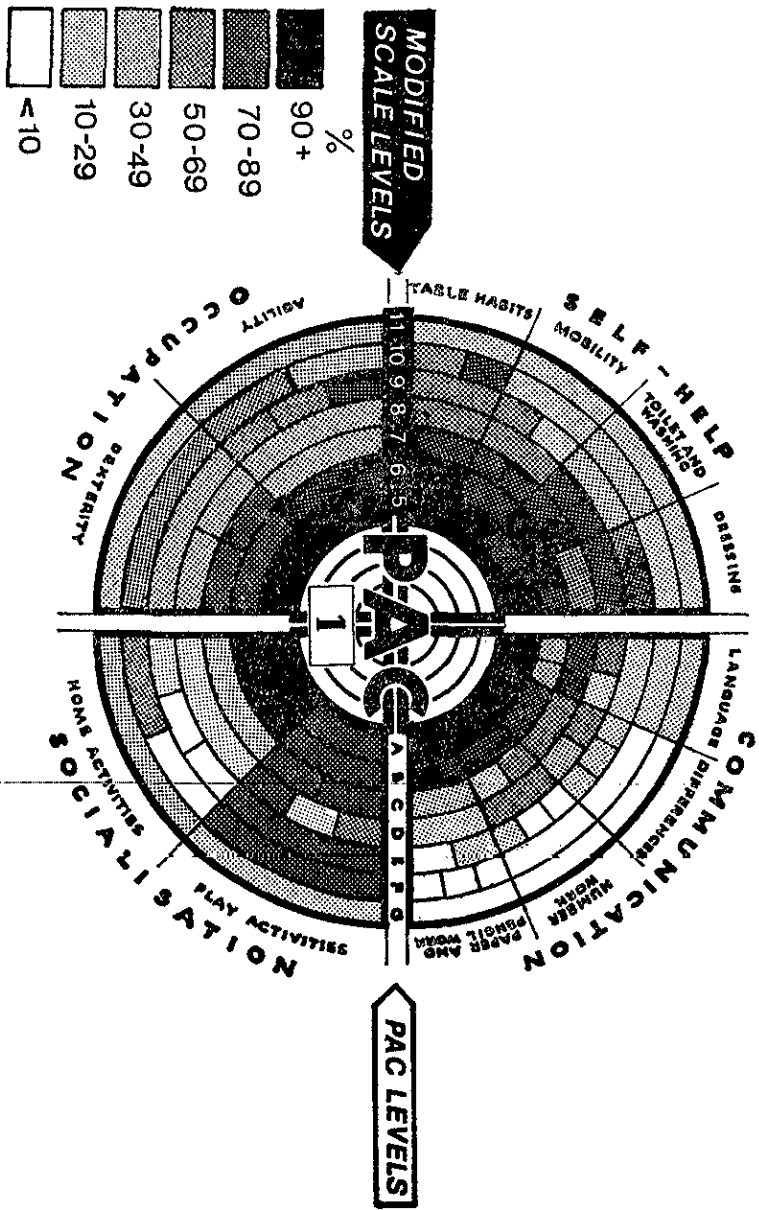


Figure 2 Percentage of the moderately impaired group (Modified Scale Levels 3-4) attaining specific items on P-A-C-1 Form.

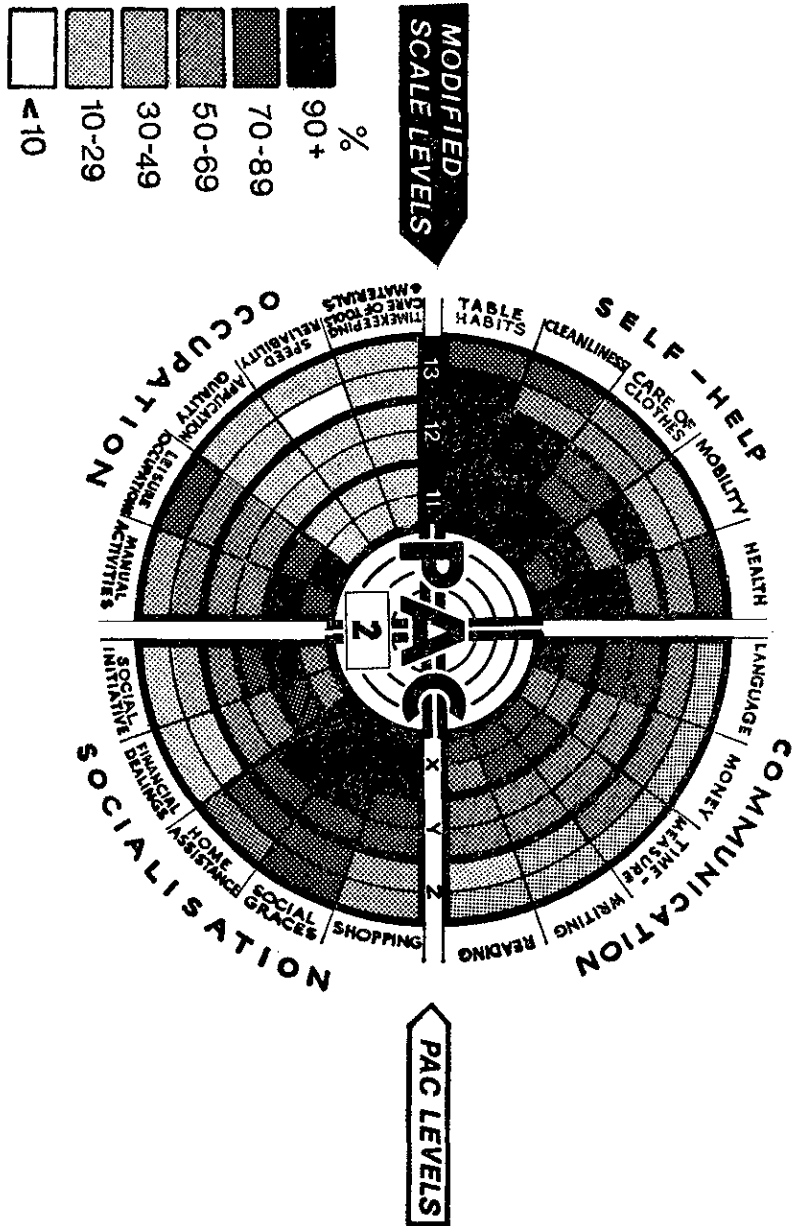


Figure 3 Percentage of the mildly impaired group (Modified Scale Levels 11-13) attaining specific items on P-A-C-2 Form.

social competence. In the moderately impaired group (Figure 2) the item 'acts out stories heard' was scored by a much smaller percentage than might be expected, whilst 70-89% were able to 'pour liquids' (Figure 3) which is supposed to be a more advanced task. Even in the mildly impaired group some advanced tasks such as 'hobbies' were attained by over 70% of subjects, whilst others, supposedly less advanced, were passed by a much lesser proportion.

Generally the attainment of social skills tends to become more uneven at the higher levels of competence. This may reflect the greater proportion of skills and behaviours that depend upon learning rather than maturation, or else it could be a reflection of the more extensively researched milestones in early childhood development. 'Self-help' skills were consistently more likely to be attained than skills in the areas of 'Communication', 'Socialisation' and 'Occupation'. A possible explanation for this is the nature of the skills involved, and especially because the 'Self-help' skills are the behaviours most commonly used and necessary for coping with everyday life. 'Communication' skills were, for each of the six groups, the skills least well attained. At the lower levels of competence, this was due to the lack of speech development whilst the deficiency among the more competent subjects was the result of a general lack of understanding of matters which played a minor role in the subject's experience — financial matters, concepts of number and time, reading and writing. It may be that 'communication' skills are less easy to test and assess than other skills, but, for whatever reason, the obvious deficiency in this area throughout all levels of social competence indicates a need for action to remedy an obvious and common imbalance in the development of this area of social competence.

In our survey (Krupinski *et al*, 1981) we were able to relate the Index to Social Competence to other variables, and especially to the assessed need for placement in an institution. As expected, the index was strongly correlated with the level of mental retardation (—0.70), additional impairment score (—0.51), age of the subject (0.41), restrictions upon family life (—0.41) and to a lesser extent with behaviour problem score (—0.33), age of the parents (0.32) and use of services (.28). In an univariate analysis the Index was the variable most strongly correlated with the assessed need for placement (—0.33), explaining 10.8% of the variance. It took also the first position in a stepwise multivariate regression analysis with a 'usefulness' of twenty-three per cent.²

DISCUSSION

The results of our survey have shown that the level of social competence should be assessed in community surveys of mental retardation. That level seems to have greater bearing on the behaviour of the retarded, the use and needs for services, than the level of retardation assessed clinically or measured by intelligence tests. Gunzburg's Progress Assessment Charts proved to be a satisfactory instrument to measure social competence. They are easy to administer, and in contrast to the Vineland Social Maturity Scale (Doll, 1965), do not have to be administered by qualified psychologists, but can be used by all kinds of interviewers and field workers after a relatively short training. The Modified Scale of Social Competence constructed by us provided an overall measure of social development using all the P-A-C forms. The items included in the Modified Scale were analysed to determine whether the scale and its four subscales could be considered as Guttman scales, which are both unidimensional and cumulative (Guttman, 1956). The results of the analysis showed that for the four sub-scales the coefficients of reproductibility were above 0.9 and the coefficient of scalability 0.8; 'Self-help': .9407, .7967; 'Communication': .9505, .8162; 'Socialisation': .9518, .8242; and 'Occupation': .9457, .8187. This means that the selected items formed a Guttman scale and their selection and ranking were appropriate.

² The 'Usefulness' of each variable in the equation is defined as the percentage amount R^2 would drop if the variable were removed from the regression equation and the other variables appropriately re-weighted.

Less exact was our assignment of ages to each of the thirteen levels of the scale. Gunzburg's Social Competence Index compares the development of the individual with that of the group for which the specific form was designed. We used items similar to those included in the Vineland Social Maturity Scale to approximate the chronological age of normally developed children to each of our levels. Whilst we acknowledge the limitations of such an approach, we do not believe that it affected the values of our Index of Social Competence, especially as our results were presented in five broad groups (see Table 3).

The graphical use of the Progress Assessment Charts (Figures 1-3) revealed unevenness in social development within specific groups. Whilst differences in attainment skills between the four areas are understandable and explainable, the noted discrepancies in mastering specific items could be due to their improper classification. Describing the construction of our Modified Scale we explained why we selected some of the items for its development and omitted others. Gunzburg agrees that 'there is in fact, less agreement among researchers in the ranking of skills than one might wish'. Nevertheless, the P-A-C forms are constructed in concentric circles with 'all skills which, in normal development, should appear at approximately the same time, placed on the same level'. However, there has been insufficient work done to test whether this assumption is correct.

Gunzburg designed his Progress Assessment Charts for the use in training and education of the mentally handicapped. Because of this he felt that the attained skills of the tested individual should be compared with norms for a similar group of handicapped to indicate realistic gaps in his social development. There is, however, no reason why this instrument could not be used in epidemiological studies to measure the social competence, social age and evenness of development of mentally retarded in the community. This would require, however, some re-examination and changes in the existing charts:

1. The Charts should constitute a clear continuous scale with the higher levels of the lower chart overlapping with the lower levels of the next form.
2. A survey of a large population of normal infants, children and young adolescents should be carried out to determine the chronological ranking of specific skills and the ages at which they are normally mastered.
3. The results of the survey should help in rearrangement of the specific skills in concentric circles to ensure their proper assignment for each level, equated with the chronological age of normal development.
4. The selection of the chart in community studies should be based on the apparent level of social competence rather than on the chronological age of the subject.

We believe that these suggestions will not preclude the use of the P-A-C in educational and training settings, as has been done until now, but will make them also a reliable multifacit measure of social competence of a large population.

ACKNOWLEDGEMENTS

The authors wish to thank the Mental Health Donations Trust Fund and the Premier's Department for a special grant to finance the survey.

Dr. H. C. Gunzburg and SEFA (Publications) Ltd. for permission to reproduce the Progress Assessment Charts.

Mr. Norman Carson, Statistical Investigation Officer of the Institute, who was responsible for the processing of the data.

Bronwyn Harris and Maria Taranto for typing the manuscript.

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