

SYMPOSIUM ON PARENTS AND PROFESSIONAL STAFF

I. PROBLEMS OF MANAGING MENTALLY HANDICAPPED CHILDREN AND ADULTS:

A comparison of the different perceptions of parents and staff

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INTRODUCTION

Kushlick, Blunden and Cox (1973) in Wessex devised and reported a relatively quick and easy method for use by direct-care staff in large scale surveys to rate management problems of mentally handicapped people by social and physical incapacities (SPI) and speech, self-help and literacy (SSL) problems. In a survey of almost 7000 mentally handicapped people a high degree of reliability had been achieved and the tests stood up well to practical usage. The method is now widely used and the Sheffield Case Register (see Martindale, 1976) has been using it since 1975 but with the added benefit of two highly trained interviewers (Home Visitors) who structure standardised interviews with direct-care staff and parents to obtain the ratings. One might therefore expect even greater reliability and validity in the Sheffield ratings than was found using the original methodology.

The advantages and limitations of SPI and SSL ratings have emerged gradually. The reporters of the original methodology themselves recognised that assessments of behaviour were necessarily very crude (Blunden, 1973). May (1979) concluded from an admittedly small pilot study that the reliability of behaviour ratings was not at an acceptable level. Moreover, Kushlick *et al.* (1973) reported that there was a tendency for school and training centre staff to rate subjects better than nursing staff. The explanation given was that day-care staff were not in contact with clients during the difficult periods of getting-up, bedtime, night-time and weekends and did not see a representative sample of the clients' problems. However, it may be the case that some problems are only manifested in certain environments which the clients do not like, *e.g.* the ward.

This paper compares SPI and SSL ratings collected at the same time in both the day-care unit (*e.g.* school or A.T.C.) and the residence (home or unit) for a large sample of children and adults on the Sheffield Case Register. The different perceptions of problems by parents and staff are compared and it is believed that this is the first reported survey of the use of SPI/SSL ratings with parents.

METHOD

Since 1st July, 1978, collection of SPI and SSL ratings by Home Visitors for clients on the Sheffield Case Register has been related to the dates of birth of clients who are followed-up at ages 3, 6 and every two years to 18, 21, 25 and then every five years to the age of 65. These ages were determined as a compromise between 'workload' and 'developmental' considerations. The Home Visitors work through quarterly computer listings of clients due for follow-up and SPI and SSL information is collected in both place of residence (from parents at home or staff in residential units) and place of day-care (school or A.T.C.) where appropriate. This report is based on the information collected in the two years ending 30th June, 1980. It was readily accessed from the Register's own mini-computer to obtain printouts for analysis by age-groups (under and over 18 years of age) and places of day-care and residence (including home) for the SPI and SSL ratings.

100% samples were not available because of reasons described in the results and discussion sections below.

For each SPI and SSL item, cases with *minor* and *major* differences between residential and day-care assessments were calculated using the method of Kushlick *et al.* (1973). This classifies *minor* differences between ratings as those in which ratings are *adjacent* (e.g. speaks nothing — speaks odd words) and *major* differences as those in which ratings are *not adjacent* (e.g. speaks nothing — speaks sentences). The minor and major differences were then classified by whether the *better* ratings were given in the day-care or residential settings. In each main service category for each SPI/SSL item, the percentage of cases in which residential and day-care assessments were identical was calculated.

For the under 18 years of age group, the analysis includes information collected for 'children' living at home attending special schools other than ESN(S) schools. These have been categorised by headteachers as 'at risk' of using mental handicap services for adults (using an experimental set of criteria to be described in a future publication). It is known that up to 30% of children leaving special schools other than ESN(S) schools in Sheffield use such adult services (for varying periods).

RESULTS

The results for 'children' under 18 years of age and 'adults' 18 years of age and over are analysed separately. To simplify presentation of the main findings, only when the degree of identical information between different sets of ratings was less than 80% were major and minor differences studied in detail. Where percentages exceeded 80%, numbers of major and minor differences were too small to consider.

Children under 18 years of age

Information was not available for 27% of those in residential care (mostly recent admissions), 14% of those in ESN(S) schools living at home (mostly young children) and 33% of other children 'at risk' living at home in Sheffield. The numbers of those remaining were 233 ESN(S) children (for whom comparative SPI/SSL information was available for 213), 120 children at other schools (for whom comparative information was available for 97) and 51 children in long-term care (for whom information was available for 43). The remainder of this section concerns the 353 'children' for whom comparative information was available. Those in different types of residential care are not differentiated because of small numbers. The percentages of cases in which the two sets of ratings were identical are shown for main SPI and SSL categories and different service groups in Table 1 below. Equivalent 'reliabilities' (Kushlick *et al.*, 1973) are shown for comparison in brackets.

Table 1:

SPI/SSL item	% identical ratings by Service Groups:			Total
	Residential Care	ESN(S)	Others 'at risk'	(Kushlick figs. in brackets)
Walking	86	81	90	84 (92)
Incontinence	72	77	88	80 (80)
Behaviour	56	59	62	61 (76)
Speech	91	85	94	88 (82)
Self-help	83	60	74	67 (78)
Literacy	91	85	76	83 (78)

Overall, the percentages of identical information were lower for walking, behaviour and self-help, virtually the same for incontinence and higher for speech and literacy ratings by comparison with reliabilities found in the original survey of Kushlick *et al.* (1973). Moreover, there were some highly specific differences between main service groups as shown

in the table. For service groups and items in which the degree of agreement between assessments in place of day-care and residence (home or unit) were less than 80%, major and minor differences were distinguished. Whilst many differences were minor, some noteworthy major differences were found. For those in *residential care*, major and minor differences were noteworthy in the case of incontinence and behaviour and were almost equally divided between the better assessments being obtained in the place of day-care or the residence. However, for the behavioural sub-item of *destructiveness* more better ratings (10 minor and 5 major) were obtained in day-care assessments than in the residences (4 minor and 3 major). The noteworthy data for ESN(S) children *living at home* are shown in Table 2.

Table 2:

<i>SPI/SSL item</i>	<i>School worse than home</i>		<i>No Difference</i>	<i>School better than home</i>	
	<i>Major</i>	<i>Minor</i>		<i>Minor</i>	<i>Major</i>
Incontinence	2	5	165	15	26
Behaviour	7	5	125	26	50
Self-help	—	4	128	76	5

In Table 2 there is a consistent trend for assessments from parents to be worse than from class teachers but the degree of bias varies between items — most marked differences were found between behaviour assessments.

Other children 'at risk' who were living at home showed identical trends to ESN(S) children for behaviour and self-help items but differences in assessments of incontinence were not noteworthy. However, for this group there were also some minor differences between literacy assessments which were equally divided between 'better' assessments being given by parents and teachers. It is interesting to compare overall 'dependency' when *best* assessments of individuals (from place of residence, home or day-care) are used and when the *worst* assessments are used. The differences depend upon the item and service group under consideration and range from 5% to 32% of the numbers followed up. This is therefore the range of error which can occur in 'dependency level' surveys of children arising from different perceptions of raters, environmental differences, etc.

Adults over 18 years of age

The percentages of adults for whom no information was available were much greater than for the children above for several reasons. In the period of the survey (2 years) one would have only expected to follow-up two-fifths of the adults because of the 5-year follow-up interval. In addition many did not have a separate day-care service (e.g. because they either worked or stayed on the wards) and many received no services and remained at home. In the event comparative information was available for 104 adults in residential care and 186 living at home who attended A.T.C.s. Table 3 is the equivalent for adults of Table 1 for children.

Table 3:

<i>SPI/SSL item</i>	<i>% of identical ratings:</i>		<i>Total (Kushlick figs in brackets)</i>
	<i>Residential Care</i>	<i>Living at home attending A.T.C.s</i>	
Walking	97	80	86 (92)
Incontinence	88	91	90 (80)
Behaviour	77	73	74 (76)
Speech	93	90	91 (82)
Self-help	94	70	79 (78)
Literacy	84	80	81 (78)

The percentages of identical information for the mobility rating only were lower than in the original survey (Kushlick *et al.*, 1973). For behaviour, self-help and literacy, the percentages were roughly identical to reliabilities in the original survey and for incontinence & speech ratings, percentages exceeded reliabilities in the original survey. Overall, higher degrees of agreement between ratings was found for the adult group than for the children in Table 1 except in the case of literacy. Some specific differences in service groups were found nevertheless (as was the case for children). For those in *residential care*, only behaviour assessments showed noteworthy differences. Aggression, destructiveness and self-injuring behaviours tended to be rated as less severe by day-unit staff than residential staff albeit in a minor way in most cases. For those *living at home attending A.T.C.s*, the noteworthy figures are shown in Table 4.

Table 4:

<i>SPI/SSL item</i>	<i>Day-care worse</i>		<i>No Difference</i>	<i>Day-care better</i>	
	<i>Major</i>	<i>Minor</i>		<i>Minor</i>	<i>Major</i>
Behaviour	13	5	135	19	14
Self-help	-	4	131	51	-

In Table 4, there is a clear indication that parents assess self-help abilities and behaviour problems (particularly destructiveness and attention-seeking) as being greater in extent than do A.T.C. staff (but usually to a minor degree).

When the *best* and *worst* assessments of individuals (from home, residence or day-care) are used to obtain overall 'dependency' figures, the differences obtained depend upon the item and service group considered but range from 0 to 23% of the numbers followed up. This range of error can be introduced into 'dependency level' surveys of adults arising from different perceptions of raters, environmental influences, etc.

DISCUSSION

The results in this report are based upon 78% of children and 32% of adults from Sheffield in day and/or residential services for the mentally handicapped in the city who were followed-up between 1st July, 1978 and 30th June, 1980 and for whom comparative SPI and SSL information was collected from both place of day-care and place of residence (or home). The missing information arose from new referrals to the Register whose follow-up date had been missed, cases in which home visits had been prevented for 'social reasons' (e.g. illness, inconvenience) and because some people in residential care did not have separate day services (particularly those in old hospital units). It is not thought that this missing information for either children or adults biased the results in any way because the method used meant that all children and a 40% random sample of adults on the Register were the potential samples from whom information was sought in the first place. In general, the degree of agreement between the two sets of SPI and SSL ratings collected in day-care and residence for each individual was high. For mobility and speech ratings the percentage of cases in which information was identical was greater than 80% for both children and adults in all the different main service groups. The percentages were similar to (in the case of walking) or in excess of (in the case of speech) those observed in the original survey of Kushlick *et al.* (1973). Clearly (and with the possible exception of young children) problems in mobility and speech tend to be easier to observe more accurately than is the case with other items in this survey. These items would also be expected to be independent of in which environment and by whom they were observed. Where differences were observed in the ratings, they tended to be minor. Differences in mobility ratings may have arisen because some units do not have many steps or stairs and it may not have been recognised therefore that some people in those units had problems negotiating them. For speech, it may be that where differences arose, it was because of special relationships between the

clients and the raters (e.g. parents) which tended to lead to more optimistic ratings, i.e. a speech rating depends not only on what a client produces but also on the ability of those spoken to to understand it! In this survey, *comprehensibility* of clients speech was not studied.

Leaving aside these items in which very high agreement between ratings were found in all cases there are some items for some main service groups for both children and adults for which considerable differences between day-care and residential (or home) assessments were observed. The same Home Visitor carries out both the residential and day-care assessments for each individual and individuals are selected at random. Deficiencies in *inter-rater* reliability therefore only affect differences between individuals followed-up (*not a major purpose of this paper*). Intra-rater unreliability (minimised by the Home Visitors training and structured interviews) could not lead to systematic biases towards better ratings being obtained in either day-care or residential assessments in general. Differences in ratings of individuals must be assumed to reveal real differences therefore in the perceived problems of the same individuals between the day placement and where he/she lives. The rest of this discussion is aimed at explaining how these differences may arise. Because of the different influences which may affect incontinence, behaviour problems, self-help skills and literacy respectively, the items are considered separately.

Incontinence

For other children 'at risk' and adults in all categories, the degree of agreement between the two types of incontinence ratings is greater than 80%. This could be explained by the fact that persons in these service categories generally tend to have a lesser degree of dependency — continence is usually relatively well controlled. Persons with severe incontinence are usually excluded from A.T.C.s in Sheffield.

For children in residential care and those attending ESN(S) schools, more cases than not have better incontinence ratings to varying degrees from the day-care assessments. Schools tend to have routines for the management of incontinence so that accidents are perhaps less probable during the day for some persons living at home. Amongst those living in children's residential units there are considerable incontinence problems some of which are only present at night-time or possibly in the evenings (often when enemas are given). It may be that teachers are sometimes unaware of these problems at night thus leading to the observed differences in ratings. A small number of people do seem to present worse problems during the day, however. It is difficult to generalise about this group and the following factors may all be relevant: Occasional incontinence problems during the day may arise as a result of stress, excitement or another reaction to the day-care environment; Some parents may have a different 'tolerance' level than day-care staff; Some children's 'personal habits' may mean they are less incontinent while at home. For 12% of ESN(S) school attenders, there are no problems at all at school but severe problems at home. This is a fairly large group (26) demonstrating both the value of incontinence management programmes during the day but also a group whose parents may benefit from more advice about incontinence training. If children could be helped only to operate at their known present best at all times with respect to incontinence the numbers who have incontinence problems could be reduced from 63% to 44% of children in residential care and 46% to 27% of ESN(S) attenders with consequent savings in parental and staff time (not to mention aids) and increased personal esteem amongst the children.

Behaviour problems

Of all the items studied, the lowest levels of agreement between day-care and residential (or home) assessments occur for at least some behavioural items for all service groups for both children and adults. There are many psychological and psychiatric theories concerning deviant and inappropriate behaviour which differ basically in their attitude towards the effect of the 'environment'. It is not the purpose of this paper to examine these different

theories as possible explanations for the findings about behaviour problems. Nevertheless, the fact that they exist alerts one to the subtlety of effects and it is perhaps not surprising that least agreement between residential and day-care ratings in this survey has been observed for behaviour problems. This was also expected from previous work (see 'Introduction').

Considering first children living at home, more tend to display aggressive, destructive, hyperactive and attention-seeking behaviours at home than at school and many of these cases are severe at home but for whom there are no perceived problems at all at school. Amongst the adults living at home, the same is true for destructive and attention-seeking behaviour but not for aggressive and hyperactive behaviours for which an equal number of trainees seem to be worse at the A.T.C.s. By contrast self-injuring behaviour in both children and adults shows a high degree of agreement between day and home ratings. These observations are not easy to explain but the following thoughts seem worth considering.

In the first place, the tolerance and expectations of parents may be conditioned by a knowledge of other normal children and adults whereas the ratings of special schools and A.T.C.s may be subject to different norms — the guidelines for behaviour ratings are more open to this kind of bias than other aspects of the SPI and SSL ratings (see 'Introduction'). It is perhaps more noteworthy to strike ones parents than a classmate or fellow A.T.C. attender. Secondly the routine of a day in a special school or A.T.C. is likely to be more organised and supervised than in the freer atmosphere of home in which there may be more opportunity to behave 'badly' during unsupervised hours. Moreover some behaviour problems may occur as the result of deeper and/or closer relationships with the family compared with the larger social groups in A.T.C.s and schools. It is also possible that some behaviour problems are specific reactions to certain times of the day (e.g. bedtime). As children grow older, parents tolerance levels change regarding aggressive or hyperactive behaviours or it could be that persons exhibiting such behaviours tend to be admitted to residential care. Alternatively, aggressive and hyperactive behaviour may become 'burned up' as a child gets older but if these suggestions are true, why destructive and attention-seeking behaviours do not also show these trends between childhood and adulthood is not at all clear. Parents often refer to this kind of effect during home visits. Self-mutilating behaviour tends to be a severe problem only amongst the most profoundly retarded and seems to go on in a stereotyped way at all times in all environments once established. It is very difficult to control.

Turning now to those in residential care, for children more display destructive behaviour in the residential units than when at school or nursery but other problems seem to be roughly equally divided between being better in the place of day-care or the place of residence. For adults, aggressive, destructive and self-injuring behaviour tend to be worse in the residential units than in the day-care units. Perhaps these trends reflect the activities in the units (or lack of them) or it may be partly due to the different reactions of residents to the people they 'live' with and the people they see during the day.

Whatever the subtle reasons which account for these findings, it can be said with some degree of certainty that behaviour problems manifest themselves in different ways and depend upon the units attended at different times. About half of the children in residential care and one third of those at home display severe or mild problems of behaviour at some time in the day but only about 30% of those in residential care and 10% of those at home have problems all day (and night) long. The same trends are true of adults: about half of those in residential care and 20% of those at home having problems some time in the day but only about 25% of those in residential care and 2% of those at home have problems all day (and night) long. *It is possible that figures on behaviour problems amongst the mentally handicapped can be distorted to these extents in surveys of dependency levels.* In view of the current controversies concerning medium secure units and the management of severe behaviour problems in different kinds of units, the findings of this survey alert decision-makers, planners and managers to the fact that many behaviour problems only occur at certain times in certain places and also to the fact that many problems are only

known to and born by parents or residential staff and not by staff in day-care units (and vice-versa). These facts need to be considered carefully by those responsible for the policies towards and management of behaviour problems.

Self-help

Both children and adults living in all types of residential care have a high degree of agreement between day and residential assessments. However, for both children and adults living at home, parents have a less optimistic view of their capabilities with respect to feeding, washing and dressing themselves than do teachers and A.T.C. staff. Again, the question of standards is raised but also it must be said that getting up and going to bed are the times at which dressing and washing skills are most tested and only parents are present at these times. During the day washing and dressing skills may not really be fully exercised. It seems that unknown to schools and A.T.C.s, up to one third of children and adults could benefit from even more training in these areas of daily living *in the environment in which they actually use the skills*. However, it must be said that the different perceptions are minor in extent in all cases.

Literacy

As with self-help skills, there is a high degree of agreement between day and residential assessments for reading, writing and counting for children in residential care and adults in hospitals (for whom the general level of achievement is very low). However, for children at home attending non-ESN(S) schools, teachers in a few cases have a more optimistic view of a child's reading skills (but interestingly not of writing or counting skills). This is intuitively understandable. Other literacy skills in all childrens and adults groups are distributed with roughly equal numbers of better and worse ratings in the day-care assessments. The exceptions may confirm the particular priorities and concerns of the different hostels with training residents for different aspects of everyday life.

IMPLICATIONS OF THE RESULTS

As far as the services are concerned, the results of this report show that there are significant percentages of both children and adults whose parents have to cope with either mild and severe problems with incontinence, behaviour, or self-help in the home which are not apparent and maybe not even known about by teachers and training centre staff. The question arises as to whether this could be avoided in some cases by attempting to build up even better liaison between schools, A.T.C.s and families and by attempting to provide greater support to the home in such cases. This is one aspect in which the work of community mental handicap teams can be very beneficial.

On the other side of the coin, there are few cases in which problems only arise in the schools and training centres and not at home. Here again the importance of improved liaison between home and centre is highlighted and some suggestions about general policies for the management of behaviour problems and incontinence have been made. As far as the methodology used is concerned, the results demonstrate the importance and value of collecting SPI and SSL assessments in both place of residence (or home) and place of day-care. It has been shown feasible to collect the information from parents and it has been shown to what degree the two different assessments for the same individual can vary.

CONCLUSIONS

Whilst most problems with social and physical incapacities (SPI) and speech, self-help and literacy (SSL) skills amongst mentally handicapped people are consistent in all environments at all times, many are specific to particular units and do not manifest themselves at all times. Problems for families or residential care staff may not be apparent to teachers or A.T.C. staff and vice-versa. It is recommended that this be taken into account in considering the results of 'dependency level' surveys and their implications for services particularly with

regard to behaviour problems and that consideration be given to providing means to improve liaison between families (or residential staff) and schools or A.T.C.s. Community teams can have a very important role in this respect by preventing, or at least delaying admission to long-term residential care by helping families to cope with their practical everyday problems.

SUMMARY

The survey compares SPI and SSL assessments of 78% of children and 32% of adults on the Sheffield Case Register in both place of day-care and place of residence (or home). Identical ratings and different ratings for different service groups for children and adults are compared and related to causative influences and the methodology used for collecting the information. It is concluded that some clients may benefit from greater liaison between units and their families and the need for community mental handicap teams was supported. Some suggestions for policies towards the management of behaviour problems and incontinence are made.

References

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