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Doctor of Clinical Psychology Degree

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This volume was submitted in partial fulfillment of the degree of Doctor of Clinical Psychology AGE RECOGNITION

IN ADULTS WITH INTELLECTUAL DISABILITIES

and

RESEARCH PORTFOLIO

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Small Scale Service Evaluation Project

An Evaluation of Staff Satisfaction and Affect in a Unit for Men with Learning Disabilities and Serious Challenging Behaviours

Prepared in accordance with instructions to contributors to 'The British Journal of Learning Disabilities' (See Appendix 1.1) An Evaluation of Staff Satisfaction and Affect in a Unit for Men with Learning Disabilities and Serious Challenging Behaviours

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SUMMARY

Clients who exhibit challenging behaviours live in a social context which should be taken into account in order to understand and treat the behaviours. This context includes the characteristics of staff and their satisfaction with the whole culture and environment in which they work. The social context will also affect and be affected by staff feelings towards the clients. This paper provides an examination of such factors in a traditional unit for those with challenging behaviours and investigates a wider range of areas of staff affect than considered in previous research. Results indicate that, although the staff group showed a similar level of perceptions of staff support to another National Health Service ward quoted in the literature, staff satisfaction was not high and could be improved considerably in terms of management support. However the level of satisfaction in working with clients was high, as were the perceptions of practical support from ward colleagues at times of crisis.

In particular, this project uses a new 13 item analogue measure, the Attitudes to People who display Challenging Behaviours, which includes both positive and negative areas of affect, and demonstrates the coexistence of these in unit staff. The level of positive and negative affect does not vary noticeably relative to feelings of whether staff members feel well supported by the service.

3

INTRODUCTION

Although, in the last decade or so, many people have moved successfully from large institutions into community care, there remain problems in the placing of adults who seriously challenge services. In many areas there are small specialist units for such adults, developed within a community setting as recommended by the Mansell Report (Mansell, 1992). However, there are still many units within larger traditional institutions. There has been much debate over the provision of such units, and arguments for and against these are summarised in Table 1 (after McConkey, 1994).

Insert Table 1 here

Definition of Challenging Behaviour

The most widely accepted definition of challenging behaviour is that of Emerson, Cummings, Barrett, Hughes, McCool & Toogood (1988, p.16) which states this to be 'behaviour of such an intensity, frequency, or duration, that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit, or deny access to and use of ordinary community facilities'. The people who exhibit challenging behaviours of violence to people and property, or self-injury, within this definition, are those who are the most likely to be placed within a 'challenging behaviour unit'.

Treatment of challenging behaviour has changed over time from the use of behaviour modification techniques in isolation to an increasing emphasis on understanding and treating the reasons for the behaviour (Repp, Felce & Barton, 1988). Increasingly there has been a greater recognition of the social function that may be served by the behaviour (Derby, Wacker, Sasso, Steege, Northup, Cigrand & Asmus, 1992). Gradually challenging behaviour has therefore come to be seen as a difficult and complicated social pattern rather than being something located within an individual, and this social context has come to be seen as a two-way relationship (Clements, 1992).

Additionally, the area of challenging behaviour is one which is reported to be a major contributor to staff stress levels (George & Baumeister, 1981; Bersani & Heifetz, 1985) and this area has also been associated with low staff morale, high staff turn-over and high staff absences, and in the development of negative attitudes and feelings towards the clients (Cherniss, 1980; Maslach & Jackson, 1981). This social context, then, both influences and is influenced by, those people with challenging behaviour, and there has been an increased recognition of the need for supportive systems for staff working in this field (Hewson & Walker, 1992).

However, staff have different views about the reasons for the behaviour of their clients and this may influence their attitudes. Hastings, Remington & Hopper (1995), for example, showed that experienced staff held views about the causes of challenging behaviours consistent with current research, whereas inexperienced staff viewed challenging behaviour quite differently, with a greater emphasis on environmental antecedents and the role of attention, and less belief in the behaviours being operant in the social environment.

Other research has looked at the amount of negative affect which staff experience in relation to those exhibiting challenging behaviour (Hastings, 1993; Bromley & Emerson, 1995). Fallon (1993), reflects on initial staff feelings of empathy, optimism and curiosity and fear changing to frustration, anger, detachment and guilt over time. Such negative affect of staff influences the social context in which the clients live day to day (Maslach & Jackson, 1981; Garety & Morris, 1984).

From these studies, then, it can be seen that what is important is not any one or more factors, but the inter-relationship of many.

Background to the Current Study

In a recent paper, Hastings & Remington (1995) reported on the negative affect that staff experience in working with a person with learning disabilities who showed challenging behaviour. They found that this was influenced by both the type of behaviour as well as the degree of experience of the staff member. Self-injury and aggression were associated with more negative emotions than stereotypy, and more experienced staff rated challenging behaviours as less disturbing and they described less fear, than did inexperienced staff. They concluded that staff may become less inclined to participate in intervention programmes to reduce the challenging behaviours as their negative emotions reduced over time, that inexperienced staff who have negative affect will not wish to follow such programmes, and that experienced staff require more extreme behaviours before intervention.

However, Bersani & Heifetz (1985) had indicated that the sources of stress were made up of client related stress and work related stress, and that stress and satisfaction were not 'polar opposites' but were separate dimensions. Therefore, perhaps both affect and staff support are areas which need to be investigated in conjunction with one another.

Generally, research studies have looked at *negative* affect (Bromley & Emerson, 1995; Hastings & Remington, 1995) and have considered areas of affect such as anger, annoyance, despair, fear, sadness, disgust, the degree that staff are disturbed by the behaviour etc. However, staff in the Hastings & Remington project (1995), in response to an open-ended question, put forward the *additional* emotional reactions of frustration or upset, feeling a need to help, helplessness, empathy or sympathy, concern, confusion and discomfort. It may be useful,

therefore, to consider the coexistence of both negative *and* positive affect in a challenging behaviour environment within the context of the degree of staff satisfaction with their support network.

This paper, therefore, aims to extend the information available on staff satisfaction and affect experienced by staff (and thereby contributing to the social environment for clients) by examining one particular unit in a traditional setting. It also aims to examine the relationship between staff satisfaction and affect, and to take into account personal characteristics of staff within that group which may influence the measurement of the outcome.

METHOD

Setting - The Challenging Behaviour Unit

This unit is located within a large institution and caters for males only. The institution is gradually declining in overall numbers, but the unit remains fully used and in high demand. It is locked (with double doors, both locked), serves 24 men and has a staff of 25 in total, including part-time and night staff. Clients exhibit a variety of challenging behaviours, some high frequency, others low frequency but high severity. Some residents are detained by reason of a Mental Health Act order or through diversion from the courts, and others are placed there following multidisciplinary clinical discussion. The unit is traditional in style, with a large dormitory area (observed) and several living areas. The approach of the staff may be described as within a model of non-aversive treatment (La Vigna, 1986). There is evidence of good multidisciplinary working and care-planning.

Measures

The following measures were used to evaluate staff support and to measure affect, and demographic information (including client and staff details such as numbers, sick leave, incident reports etc) was obtained from the Care Manager and Charge Nurses to establish the climate in which the staff and clients live and work. They are grouped according to the area of enquiry.

Perceptions of Staff Support

1) The Staff Support Questionnaire (Harris & Thomson, 1993), (SSQ).

This is a 24 item scale looking at the following areas - role ambiguity/clarity, practical support in crisis situations, identification of 'at risk' situations and overall job satisfaction. It was used in a study funded by the Department of Health to evaluate services received by people with learning disabilities and challenging behaviour and has been shown to be a reliable and valid measure. (See Appendix 1.2)

2) Organisational Variables (Hewson & Walker, 1992) (OV)

These are five variables considered to be important in terms of staff support - a written statement of service aims, individual service plans, weekly staff meetings on the progress of residents, having a nominated Key Worker and a staff appraisal system. (See Appendix 1.3)

Affect

3) Attitudes to People who display Challenging Behaviour (APCB)

The APCB is a new measure of positive and negative affect developed by the author. It was designed to extend the work of Hastings & Remington (1995). It is a 13-item analogue measure. (See Appendix 1.4)

Staff Characteristics

4) The Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1964)(M-C).

This measure was used to determine the degree of social desirability shown by staff in their answers.

5) The Index of Psychological Well-Being (Berkman, 1971) (IPW-B).

The IPW-B was used to determine the overall psychological state of the staff. (See Appendix 1.5)

Staff Details, Unit Details and Client Behaviours

6) The care manager of the unit was requested to give information regarding staffing levels, sickness rates, injuries and incident reports etc.

7) A charge nurse gave information on the challenging behaviours exhibited by the clients over the last year and assessed the *severity* of these on a scale of mild/moderate/severe and *frequency* on a scale of daily/weekly/monthly or bi-monthly/occasional.

8) Staff were also asked if they would be prepared to give, voluntarily, details of their age, sex, years of experience, level of training, assaultative incidents, other unreported injuries and threats etc. alongside data from the measures.

Procedure

In order to engage the cooperation of staff in a time consuming exercise, the data was requested in two parts, with a month's interval between parts. The first part used the IPW-B and the M-C, and the second part used the OV, the SSQ, the APCB and also requested demographic information, details of injuries received etc.

Distribution of the questionnaires was organised through the co-operation of nursing staff but unfortunately this resulted in the loss of information connecting the second set to the first set of data.

Also, some of the questions on staff details threatened the anonymity of staff and many omitted to answer some questions. Although this resulted in the loss of some potentially very useful information, staff sensitivities had to be respected.

In order to check whether or not the staff in the Challenging Behaviour Unit showed different characteristics from other staff in the hospital, two of the measures, the IPW-B and the M-C, were also used with a staff group from one of the Professions Allied to Medicine for comparison.

The return rates of the questionnaires were 80% for each part of the procedure. The numbers of questionnaires were different on the two occasions due to staff sickness and holiday rotas. As occasional questions were omitted, the number of people responding is given in brackets throughout.

RESULTS

Descriptive Information

a) Challenging behaviours

Table 2 describes the types of challenging behaviours shown by the 24 residents over the previous 12 months and an estimate of severity and frequency (as described by the Charge Nurse).

Insert Table 2 here

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b) Injuries to staff

Formal incident reports comprise 24 incidents reported in the last year (1997), with 22 of these involving physical assaults. However, 13 staff noted that they had received injuries from assaults, such as small bruises, which they felt had not warranted reports. They also indicated that assaults happened to them quite frequently (4 staff recorded that assaults happened to them 'occasionally', 3 said this happened monthly and 5 stated weekly). They also recorded that verbal threats were made to 7 of them on a daily basis and 5 on a weekly basis. However, despite this, when asked how long they usually had to wait for assistance, most responses were in terms of a few minutes (n = 12), with only 2 staff members reporting times of over 5 minutes.

c) Staff sickness and turnover

Sick leave on this ward was considerably lower than in most of the rest of the hospital (around 5% compared with a hospital mean of 8%). Staff turnover in this period was 5 (1 staff member left for a developed post in challenging behaviour supporting the Community Learning Disability Teams and the others were moved due to hospital retraction and refiguring of wards).

d) Client numbers and trained / untrained staff balance

Over this period client numbers stayed around 24 and the trained / untrained staff balance remained approximately the same.

Staff Characteristics

a) Psychological well-being (IPW-B)

This showed good psychological health in the ward group (mean + 1.75, range - 6 to + 8, S.D. = 3.75, n = 20). The comparison group of a Profession Allied to Medicine also showed good psychological well-being (n = 11, mean = +1.4, range - 4 to + 7, S. D. = 3.04). A Mann-Whitney U test showed that the difference between the two groups was not significant ($p \le 0.05$, two-tailed).

b) Social desirability (M-C)

The M-C results showed that both the ward group and the Profession Allied to Medicine showed greater social desirability than the sample of undergraduates tested in the original paper (Crowne & Marlowe, 1964). (The ward mean was 19.15, the range was 11 - 29, S.D.= 5.15, n = 20; the Profession Allied to Medicine group had a mean of 15.6, range 9 - 23, S.D.= 4.23, n = 11; the undergraduates had a mean of 14.39, S.D. = 5.62, n = 110).

A Mann Whitney U test showed that the difference between the group of staff working in the Challenging Behaviour Unit and those in the Profession Allied to Medicine was not significant ($p \le 0.05$, two-tailed). Neither group had results as high as those obtained in the original paper (Crowne & Marlowe, 1964) from people who had believed that their results would be influential in their gaining employment (mean = 24.62, S.D.= 4.96, n = 285). c) Demographic and Other Staff Details

These were examined to see if these could shed any light on other important factors but, as explained earlier, many staff had omitted details which threatened their anonymity and no conclusions could be drawn.

Staff Support

a) OV

Staff had been asked if five organisational elements which had been found to be helpful (Hewson & Walker, 1992), were in place. A resume of these results follows (Full results are given in Table 4, Appendix 1.3) :

- 56.3% of the staff were aware that there was a clear written statement of aims given to them to read (n = 16).

- 81.3% were aware of the individualised service plans for each client (n = 16). - when asked if there were weekly staff meetings to monitor the progress of individual residents, almost all answered 'no' to this, quite correctly. This process is, in fact, carried out by a different format. (93.8% said 'no', 6.2% said they did not know, n = 16).

- 87.5% of staff knew of the nominated key worker system (n = 16).

- when asked if there was a staff appraisal system in regular use, as reported by the Care Manager, 56.3% of the staff did not know of this (n = 16). However, the question here asks if there is a staff appraisal system in regular use. It may be that some of the staff members did know of the staff appraisal system but they did not consider it to be regular or frequent enough. b) SSQ

The results give a mean for the ward staff of 38.5 (range 29 - 49, S. D. = 5.3, n = 16). This is very slightly lower than the mean of 40.9 quoted by Harris and Thomson (1993) for a hospital ward. A resume of the results follows (Full results are given in Appendix 1.2) and these are described according to the four sections of the SSQ :

1 - Role Ambiguity/ Clarity

The results showed that most staff members were clear about their main objectives, the expectations of their superior staff and the limits of their responsibility (76.5%).

However, most were not clear about whether their work met their superior's satisfaction (64.7% either unclear, very unclear or undecided).

2 - Practical Support in Crisis Situations

Most staff members felt they could talk to someone at work if they had difficulty in their job (70.6%). In terms of practical help if they required it, they all felt supported and almost all staff reported that help arrived in less than five minutes and were happy with this.

However, 70.7% of staff considered that they did not receive regular supervision sessions or performance reviews and were dissatisfied with this. This ties in with the results of OV where more than half of the staff answered 'no' to the question of whether there was a staff appraisal system. As discussed earlier, either they did not know of the appraisal system reported to be in regular use or did not think it frequent enough.

3 - Identification of Risk Situations

64.8% of staff felt that risk situations had been clearly identified and most of these staff members related that they had been involved in this process. However, 47.1% did not know of, or considered there not to be, guidelines for difficult

situations.

4 - Overall Job Satisfaction

This was generally low, with 41.2% of staff satisfied with the present situation at work and 52.9% satisfied with their degree of involvement in decision making, and fewer people, 29.4%, happy with the support they received at work. The earlier result, under the heading Practical Support in Crisis Situations, showed that they had good *practical* support with speedy assistance from other staff as required. The result here could show a lack of clarity about whether their work met their superior's satisfaction.

Over half of the staff agreed that they often think about finding another job (52.9%). However, this figure may well be inflated due to fears about the long-term future of staff positions in a hospital which is retracting.

Affect

Table 3 shows the means, range and standard deviations of the scores obtained on the APCB for the whole group of staff in the Challenging Behaviour Unit (not including the comparison group), and the results of the APCB are displayed in Figure 1 in relation to the staff feelings of support as measured by the SSQ. Figure 1 also shows the results for the group of people having high feelings of staff support (below the mean of the SSQ) and for the group of people having low feelings of staff support (above the mean of the SSQ).

Insert Table 3 and Figure 1 here

Table 3 also demonstrates the wide range of scores for each area of affect with the exception of 'confidence', which had a narrower band of scores (mean = 8.6, S.D.= 1.3, range = 6 - 10, n = 14).

Table 4 demonstrates which areas of affect were high (> 6.5 on the APCB scale), medium (3.5 - 6.5), or low (< 3.5) for the whole group (n = 14), for the group who felt well supported at work (n = 6) and for the group who did not feel well supported (n = 8).

Insert Table 4 here

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From Tables 3 and 4, it can be seen that staff reported that they felt that there was some possibility eventually of making change for the better in the person with challenging behaviour. Also, it can be seen that staff did indeed show a wide range of co-existing feelings, some of which may be described as positive and some negative. Most noticeable are the high results in staff members' feelings of confidence in being able to manage the clients effectively, the strong feelings of a need to help the clients and of empathy with them. Also, this table demonstrates the low degrees of feelings of disgust, excitement, despair and of anger at the clients. Of particular note is that, although there are some high areas of 'positive' affect, such as a high level of confidence in working with the clients, there are coexisting areas of 'negative' affect to a greater or lesser degree.

As noted earlier, the results of the two sub-groups, in terms of their APCB scores, can be seen in Figure 1, and Table 4 outlines the areas of affect for these groups. However, although there is some difference between the means, when the results are noted within one confidence interval, as in Figure 1, then it can be seen that the differences in this study are not sufficient to warrant further investigation.

DISCUSSION

This paper demonstrates that a much wider range of areas of affect than previously shown, may interact in members of staff working with this client group. This extends the work of Hastings & Remington (1995). The findings of the current project supports the coexistence of a range of positive and negative feelings in a staff group towards clients who exhibit challenging behaviours. The degree of staff support that staff felt in this unit for challenging behaviour appeared to be similar to other such NHS units and may well have been higher if the effects of the uncertain future of the institution were taken into account. On a practical level the staff felt confident and well supported in terms of practical assistance by others on duty, although they showed dissatisfaction in many areas with support from their superiors and from management. Pointers to the enhancement of staff support have been fed back to senior nursing staff. As noted in the Introduction, such feelings of support add to the social environment in which the clients live (Garety & Morris, 1984; Maslach & Jackson, 1981). The results of this project also support Bersani and Heifetz (1985) who considered that the sources of stress are made up of client related stress and work related stress and that stress and satisfaction are separate dimensions. In this case, the staff group of the Challenging Behaviour Unit, as a whole, had positive attitudes towards the clients, with high confidence, empathy and feelings of a need to help, and low feelings of excitement, fear and disgust, despite a degree of work-related stress. However, there was no particular distinction in areas of affect for staff relative to the degree of satisfaction with their work support network. Specific group factors were ruled out as the staff within this unit showed similar responses to the questionnaire on social desirability as another group who were employed within the same healthcare facility. The two groups were also similar in terms of psychological well-being.

Future Investigations

Due to the need to protect anonymity, several other factors that may be important, were unable to be investigated. These included the positions held by staff

members and their levels of training. It would be useful to see whether or not these influenced the attitudes of staff, and also if they altered the balance of negative and positive affect, in the way that beliefs held by staff about the causes of challenging behaviour were different in experienced and in inexperienced staff (Hastings, Remington & Hopper, 1995).

Other factors to consider would be the amount of staff experience of challenging behaviour, the ages of the staff members, the ratio of clients to staff members etc. Another aspect which may prove very important to investigate is the effect of serious assaults or of minor injuries and threats on the range and degrees of affect of those staff members assaulted or threatened.

Despite the staff group in this unit being shown to be similar to another group in the same healthcare facility on measures of psychological well-being and social desirability, and to be similar to another in terms of feelings of staff support to another NHS group in the literature (Harris & Thomson, 1993), the analysis does not take into account the *profiles* of individual staff members feelings towards the clients. It is suggested that future investigations could seek to measure these, perhaps in relation to evaluations of perceived effectiveness in working with clients exhibiting serious challenging behaviours.

For comparison purposes, it would also be useful to measure the coexistence of negative and positive affect in units other than those units for challenging behaviours.

ACKNOWLEDGEMENTS

I would like to thank the staff who took part in this study and Professor Colin A. Espie for his guidance and support.

TABLES AND FIGURES

Advantages	Disadvantages	
*Provides a controlled environment	*Removes people from their base environment; behaviour changes may not generalise	
*Can contain high frequency and high intensity episodes	*May lower the threshold of tolerance of other service settings	
*Staff become highly skilled	*May de-skill other staff; may become used as a first resort	
*Environment can be customised	*May 'silt-up' with clients who have extreme episodic behaviours	
*Can become a resource centre of skills and expertise	*Staff may become elitist or conversely isolated and demoralised	
	*May stigmatise (ex-Unit)	
	*Numbers needing service may be small; costs are high	

Table 1. Advantages and Disadvantages of Specialist Units for ChallengingBehaviour (after McConkey, 1994).

Type of challenging behaviour	Percentage of residents showing this behaviour	Frequency of the incidents as judged by Care Leader	Severity of behaviour as judged by Care Leader
aggressiveness, including threats, to people and property	71%	29% occasionally 12% monthly/ bi-monthly 17% weekly 13% daily	8% mild 17% moderate 46% severe
self-injurious behaviour	25%	8% occasionally 13% monthly/ bi-monthly 4% daily	9% moderate 16% severe
disruption/screaming name-calling/teasing non-compliance	67%	14% occasionally 25% weekly 28% daily	46% mild 21% moderate
inappropriate social approaches	46%	46% daily	46% mild
running away	4%	4% occasional	4%
overactivity	4%	4% daily	4% moderate

TABLE 2. Types of Challenging Behaviour shown over the previous yearwith Frequency and Severity Levels.

Area of affect of APCB	n	Mean score	S.D.	Range
Possibility of making				
change	12	5.4	3.2	1-9
Sadness	14	4.8	2.1	1-8
Frustration	14	5.2	2.6	1-10
Annoyance	14	4.5	2.9	0-9
Confidence	14	8.6	1.3	6-10
Empathy	14	6.9	2.4	2-10
Despair	14	3.4	2.6	0-9
Excitement	13	2.5	2.3	0-6
Anger	14	3.9	2.8	0-8
Fear	14	3.2	2.5	0-7
Satisfaction	14	5.9	2.6	1-10
Need to help	14	7.2	2.6	1-10
Disgust	14	2.6	2.8	0-8

Table 3. Means on the APCB of the staff in the Challenging Behaviour Unit (not including the comparison group) by area of affect. (Note: occasional areas had not been marked on the questionnaire by staff, so the number replying is given for each area of affect.)

Medium scores on APCB	Low scores on					
(3.5 - 6.5)	(< 3.5)					
Total group answering the questionnaire (n = 14)						
possibility of making change	excitement					
sadness	fear					
frustration	disgust					
annoyance						
despair						
anger						
satisfaction						
oup with high feelings of staff suppo	rt (n = 6)					
possibility of making change	despair					
sadness	excitement					
frustration						
annovance						
anger						
fear						
satisfaction						
disgust						
up with low feelings of staff support	(n = 8)					
nossikility of making shance	quaitament					
sedness	excitement					
sauness	foor					
inustration	diaguat					
annoyance	disgust					
despair						
satisfaction						
	(3.5 - 6.5) answering the questionnaire (n = 1 possibility of making change sadness frustration annoyance despair anger satisfaction possibility of making change sadness frustration annoyance anger fear satisfaction disgust up with low feelings of staff support possibility of making change sadness frustration annoyance anger fear satisfaction disgust					

Table 4. Scores on the APCB, represented as High, Medium and Low levels, for the Challenging Behaviour Unit staff group, and for the sub-groups of staff feeling well-supported and of those not feeling well supported.





Figure 1. Results of APCB by area of affect

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Major Research Project Literature Review

AGE RECOGNITION IN ADULTS WITH INTELLECTUAL DISABILITIES : A REVIEW OF THE LITERATURE

SHORT RUNNING TITLE

Age Recognition in Adults with Intellectual Disabilities : a Review

Prepared in accordance with guidelines for submission to 'Journal of Intellectual Disability Research' (Appendix 2.1) 26

AGE RECOGNITION IN ADULTS WITH INTELLECTUAL DISABILITIES : A REVIEW OF THE LITERATURE

SHORT RUNNING TITLE

Age Recognition in Adults with Intellectual Disabilities : a Review

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AGE RECOGNITION IN ADULTS WITH INTELLECTUAL DISABILITIES, A REVIEW OF THE LITERATURE.

ABSTRACT

The ability to recognise age in self and others assists people in developing and showing appropriate social behaviour. This area is therefore a key one for adults with intellectual disabilities. Not only is it necessary to know what skills adults with intellectual disabilities have, and the factors that are important in the development of these skills, but a good measure to assess such an ability is also required, which could then lead to ways of teaching age recognition. There are, however, very few relevant research papers to date.

This paper reviews the limited material available within the field of intellectual disabilities concerning age recognition and looks at other fields from where ideas may be drawn to throw light on this area. The findings suggest that there may be a range of factors such as intellectual ability, developmental level, age and the number of years of institutionalisation.

	KEY WOR	DS		
Intellectual disabilities	Recognition	Discrimination	Adults	Age

INTRODUCTION

Knowledge of age, both of others and self, is important in society for the development of appropriate social behaviour, and breaches of what is deemed to be socially acceptable behaviour may lead to negative views of the person by other members of society. For example, we tend to choose company for social events from around our age-band, although there are some exceptions to this 'rule'. When some behaviours are carried out by people in very different age bands this may be seen as unusual or inappropriate and may cause considerable social comment.

For many years, the principles of normalisation have underpinned the planning and provision of services for people with intellectual disabilities (Tyne, 1981). Briefly, these principles assert that people with intellectual disabilities should have the same opportunities to experience and choose the same kinds of activities and lifestyles as can anyone else, using the same means to achieve them and with specialist support and help to attain these where necessary. However, interests and behaviour shown by people with intellectual disabilities are often still not appropriate to the age of the person, and many text books discuss ways and means to encourage age-appropriate behaviour (Griffiths et al., 1989; Carr & Collins, 1992). When the behaviour shown is the preferred interaction with someone who is very much younger, it is usually assumed that the person with intellectual disabilities is selecting someone of an approximately similar developmental age or selecting someone who perhaps does not have the same skills as an adult to leave such a situation. However, occasionally the behaviour is viewed as deviant, rightly or wrongly, often with very serious consequences for the intellectually disabled person. There are, however, no standardised assessment tools to measure the ability to assess age for use either with the normal population or with people with intellectual disabilities. There is, however, mention of the need for these (Griffiths et al., 1989). Lipe-Goodson and Goebel (1983) postulate that problems in age recognition of self and others arise because many people in the intellectually disabled population lead lives that lack key events for themselves or others, such as weddings, first jobs and promotions, retirals, funerals or the celebrations and related rites of these, which act for the rest of us as markers of the ageing process. It would be useful therefore to review the literature to have a clearer picture of the whole process of age recognition and to consider how this skill may develop in children, and to see whether there are sub-groups, such as adults with intellectual disabilities, who may have particular difficulties. With this knowledge, then it may be possible to prevent, remediate or alleviate any problems. Also, due to the dearth of such research in the field of learning disabilities, knowledge of the development of age recognition skills in children may give some clues as to the difficulties there may be. This review, therefore, will look firstly at related areas including the processes of age recognition in children and in adults, the development of age perception of self, the development of the concepts of death and of gender in children, the effect of the gender of the participant on the ability to judge age, and the cues used by children in gender and age recognition. Following this, the findings from the studies into age recognition of self and others by adults who have intellectual disabilities, and their understanding of death, can be more usefully placed in context.

RELATED RESEARCH FROM A VARIETY OF FIELDS

Age recognition of others by children

Kogan et al.(1961) used a series of nine passport photographs of males and nine of females and asked children to sort them in order from youngest to oldest.

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Progressive increases in age discriminability were shown from ages four to five but there appeared to be a ceiling at around five to six years. At age four, around 50% of the children could do the task but by age five, this had risen to 90%. Stevenson (1967), using film segments, also showed progressive improvement in age discriminability although he commented that the ceiling seemed to have occurred by Grade 4 (in schools in the USA this is around nine or ten years of age). Looft's study (1971) asked children to determine the older of a pair of drawings and he also commented on the increasing linear trend with age from three years to nine years.

Britton and Britton (1969) used a series of line drawings, one set of five male figures and one set of five female figures, representing a child, an adolescent, a young adult, a middle-aged adult and an older adult. A methodological flaw in this study was the fact that the drawings used a minimal number of visual cues to depict the age of each figure thereby limiting the number of cues available to those cues selected by adults. The children were asked to select the drawing of the youngest of the series, with each selected drawing then being removed, thus effectively ranking the drawings in terms of age. Once again, results supported a progressive increase with chronological age although the ceiling in this last study was around eleven to twelve years of age, perhaps reflecting the limited cues available in the drawings, as described above.

Kratochwill and Goldman (1973) used photographs of males and females in four age bands - infant, child, adolescent and middle-aged. They found that accuracy improved from 47% at age three years to 59% at age six years and 100% at age nine. Also, Sheehan (1978) carried out a study using slides of men, asking the children to select the oldest of three presented. Younger and less experienced children were not as capable as older and more experienced children in discriminating age differences. However, 'experience' here was operationalised as the number of contacts the child was reported to have had with elderly people as related by the parents. Table 1 clarifies the main studies discussed.

Insert Table 1 here

The research literature to date seems therefore to agree on progressive increases in the ability of children to discriminate age although there is disagreement in the studies on the age at which the skill becomes well developed. However, the latter may be a consequence of the variety of differences between projects as described above. There is a lack of more recent studies in this field, however, perhaps due to the general agreement in the literature up to the late 1970s.

Age recognition of others by adults

Again, there has not been very much research in this field although Markey (1934) showed that there was little relationship between estimated age and actual age. It should be noted, however, that most studies with *children* used drawings or photographs from very wide age-bands and found that children acquired the ability to discriminate these wider age bands by around nine or ten years of age, long before adulthood.

Age perception of self in adults

The process of discriminating age in others may not be the same process as placing oneself into an age group, and a variety of evaluations by self and others (whether realistic or not) may impact upon one's placing of oneself within an age group. Guptill (1969) talked of the perception of age in others as being based on concrete, physical cues, but of self-identification as being related to how a person felt with regard to age, social ability and experience, and to physiological condition. More recently, Pinquhart (1990) reported that having positive concepts in old age were related to having good physical health and being socially active. Also, in an age where the appearance of youthfulness is highly valued, the reluctance of people to admit to their ageing process has led to their being less keen to state their real age and when stating their age to err on the younger side of the truth. Research has shown that older people tend to dissociate themselves from the category 'old' and to judge themselves younger than they are chronologically (Tuckman & Lorge, 1954; Blau, 1956; Zola, 1962; Riley & Foner, 1968). Bultena and Powers (1978) termed this a 'denial of ageing'. This tendency to deny ageing also serves to confuse the cues that are available to other people. Over the years, the concepts of 'cognitive age' and chronological age have become recognised as valuable in advertising (Stephens, 1991). There has also been research on the concept of 'contextual age' (Rubin & Rubin, 1986) and on the relational process whereby age identity is seen as a mutually constructed concept formed between participants (Coupland et al., 1991).

The concept of death in children

Related to the ability to recognise age in self and in others is the recognition of the ageing process including the processes of dying and death. Nagy (1948) researched the theories and beliefs held by children about death. From the children's remarks she categorised the material into stages of comprehension. She considered that there were three aspects of the understanding of death necessary for children of intellectually average ability to develop - that death is irreversible, universal and inevitable. She considered that there were three stages of development in this. In the first stage, between the ages of three and five years, death was denied as a normal event, rather it was unusual, considered temporary and capable of being divided into "degrees of death". In the second stage, between the ages of five and nine years, death was personified, it was not thought to be universal and it was only a distant process. In the third stage, around nine years of age, there developed a more adult perception of death. This work was supported by others (Childers & Wimmer, 1971; Hansen, 1973; Tallmer, 1974; White, 1977).

Once again, as in the development of recognition of age in others, there appears to be a gradual development with age of a full comprehension of death and dying.

The gender of children and the effect on age recognition of others

Britton and Britton (1969) reported that boys ranked their test pictures with less accuracy than girls although the differences were not statistically significant.

The concept of gender by children

As the study of the development of the concept of age is an under-researched area, especially with regard to the population of people with intellectual disabilities, research in the concept of gender may help elucidate the process.

Abelson and Paluszny (1978) looked at the development of gender recognition in normal and intellectually disabled children and found that there was a significant correlation between this ability and mental age for intellectually disabled children. In normal children gender identity was correlated significantly with both chronological and mental age and this had been achieved by around three years of age. The findings were taken to support the work of Kohlberg (1966), in whose theory of development there are three levels of gender identity :

- children recognise that they and everyone else are either male or female;

- they then realise that boys always grow up to be men and girls go on to become women;

- children then realise that there is a stability in the attributes of being male or female, similar to the realisation of the constancy of physical objects at age six or seven. Abelson and Paluszny (1978) considered that as gender identity correlated with mental age and intellectual ability, many intellectually disabled children could learn this concept in time and with additional training, and eventually they could perhaps go on to deal with more difficult concepts such as gender constancy and gender role. They also looked at the cues used to determine gender and these are considered in more detail later.

Cues used by children in gender recognition

As there has been little research in age recognition, research looking at cues for *gender* recognition may throw some light upon the issue. Abelson and Paluszny (1978), for example, reported that children use form of dress and the presence of hair on the face and head to distinguish gender. Katcher (1955) found that cues of hair and clothes were used by three year old children of normal development and that they had greater difficulty with undressed figures, and Thompson and Bentler (1971) showed that children of four to six years of age used hair style and body shape. The findings of this research, therefore, suggest that for people with intellectual disabilities, any lack of knowledge or confusion over cues in *gender* identity may make the task of age recognition of self and others more difficult. Although, the concept of sexual identity is separate from age identity and age discrimination, the two concepts appear to be learned in the early years and there may be some overlap in the cues looked for in the development of both of these concepts.

Cues used by children in age recognition

Looft (1971) showed that the most significant cue for young children in determining age appeared to be height but that older children made increasing use

of other cues. Looft (1972) showed that in a non-American culture (Sarawak, Malaysia), fatness and strength were important cues. In other research, kinship is a cue which seems to be important to children in considering age. For example, use of the terms for mother and father are often expanded to include other adults of the same age range (Brooks-Gunn & Lewis, 1979).

Hurlock (1978) reported a variety of cues that may be used by children. He stated that young children use size, hair colour, skin wrinkles, type of clothing or occupation, with such cues often being used in isolation. However, Hurlock said that by the time children are nine years old they begin to judge age more correctly, especially so in their judgements of the ages of other children.

Cues used by adults in age recognition

Pettenger and Shaw (1975) related a wide variety of features which adults used to distinguish relative age. These included hair length and style, 'chubbiness' of face, presence or absence of freckles, shape of jaw, length of nose, presence or absence of facial hair, and the breadth of the smile shown. They also commented that the number of cues given by the adults varied from one to eight, although the adults also remarked that there were influences which they could not clearly describe as being specific cues.

More recently, Charman and Clare (1992) used cues of dress codes, likely interests and behaviours, facial appearance and body posture as those cues which they themselves felt important to teach in their education group with male sex offenders who had intellectual disabilities, although it appeared to be the external cues, particularly dress cues, which were more useful to the participants.

AGE RECOGNITION OF SELF AND OTHERS AND RELATED RESEARCH IN THE FIELD OF INTELLECTUAL DISABILITIES

Age recognition of others

There is little in the way of research literature concerning the abilities in age recognition by those adults who have intellectual disabilities. However, the few research studies and reports suggest that the developmental process is similar in children of normal intelligence and in adults who are intellectually disabled, although delayed in time in the latter case. Table 2 gives an outline of research relevant to this area.

Insert Table 2 here

Lipe-Goodson and Goebel (1983), for example, studied 76 adults with intellectual disabilities from seventeen to sixty-two years of age using the sets of line drawings previously used by Britton and Britton (1969). The results suggested that chronological age is a good indicator of level of development. In the study, only 3% of the younger adults were successful in age-ranking the same sex drawings correctly but 39% of the older adults were successful, supporting the Britton and Britton study that performance improved with age.

They also looked at the relationships between factors such as age, intellectual ability and percentage of life spent in an institution, with age perception of self and others. They found that those with higher intelligence measured in terms of IQs (Intelligence Quotients) had more developed concepts of age and death when compared to those with relatively lower IQs but that these differences reduced as a function of the length of time spent in an institution (calculated as a percentage of years of life). In looking at which factors may be related to the development of such concepts as age recognition, they comment that, whereas in the normal child population both mental age and experience tend to increase proportionally with chronological age, this is not necessarily so in the intellectually disabled population. They point out that institutionalisation limits the amount and quality of experience that intellectually disabled adults get of a normal lifestyle, with less opportunity to go through normal age-related events and less chance to experience, observe and discuss others going through these processes.

Age perception of self

The Lipe-Goodson study (1983) showed that there was an effect of the percentage of life span spent in institutions on the age perception of self but that this also related to IQ. Their results showed that being successful on a test of age perception of self was related to IQ where there was a *smaller* fraction of the life span spent in institutions but not where there was a *greater* fraction of the life span spent in institutions.

The results showed that only 41% of the sample of intellectually disabled adults correctly classified themselves. Of those incorrectly classified, most erred on the younger side, which would be supported by research in the general population (Kastenbaum et al.; 1972; Bennet, 1976; Rosow, 1977). Lipe-Goodson and Goebel (1983) commented that many people with intellectual disabilities have lifestyles which often do not change as they age and therefore they may more clearly identify with a younger age group than would the normal population. Their opportunities and life experiences are more likely to be sanctioned and limited by negative attitudes of carers and of the public and the media.

The concept of death

Within the field of intellectual disabilities, a delayed developmental process has been described by Cathcart (1994) based upon the work of Kane (1979), similar to that found with children. Lipe-Goodson and Goebel (1983) found that both age perception of others and the concept of death are functions of age and that individuals with higher IQs showed higher abilities in both age discrimination and the understanding of the concept of death. This differed from the research with children of normal intelligence by Tallmer et al.(1974) which found that IQ was not significantly correlated with the understanding of death. Lipe-Goodson and Goebel (1983) suggested that for normal children or children of superior intellectual abilities, the differences in cognitive capacity may not be important. They stated that the child develops the intellectual ability to understand the concept of death with maturity, but that children with intellectual disabilities may or may not reach the levels of cognitive ability necessary to grasp the concept.

Gender of participants who have intellectual disabilities and the effect on age recognition

Lipe-Goodson and Goebel (1983) found no difference in the ability to recognise age in relation to the gender of the participant but they comment that this factor could be inter-related with the effects of institutionalisation.

Cues to gender recognition

There appears to be no research published on the cues used to distinguish gender by those people who have intellectual disabilities although the cues used in age recognition may shed some light on these.

Cues to age recognition

Once again, there has been little investigation into this area although Griffiths et al. (1989) discussed what they considered to be a need to teach discrimination of

age to adults with intellectual disabilities. However, they did not go into how this might be done or how it would be assessed, other than to mention the use of a card sorting technique for gender and age recognition. They suggested that the differences between adults and children could be taught on the basis of physical appearance, and by roles and expectations in society.

More recently, in a descriptive account of a skills training programme, Briggs et al. (1996) reported that dress cues seemed easier to use than facial cues and body posture for intellectually disabled adults. Hickey (of Briggs et al., 1996, by personal discussion) related cues such as colour of hair, presence of wrinkles, use of make-up, body size, type of clothes, height, and pitch of voice, as those cues which are given when asked for ways to assess the ages of others. Charman and Clare (1992) reported that attenders in a sex education group for male sex offenders who had mild intellectual disabilities, showed a wide range of abilities in estimating the ages of people in photographs. When asked how they would judge age, answers included asking the person, going by general appearance or by the presence of facial hair in men. However, they also suggested unreliable indicators such as height and the presence of rings to determine age. However, the group was exploratory and no formal assessment measures were used. It does, however, serve to emphasise the need for a good reliable measure which could assess the presence or absence of this concept. It has also placed this concept within the context of assessment and education about the much wider area of legal and social rules concerning sexual behaviour. The further development of such training and education groups may well prove to be of great value.

CONCLUSIONS

Research in age recognition in the field of intellectual disabilities has been extremely limited. The process may be similar in both developing children and in adults who have intellectual disabilities. The key factors have not been established. However, these could include the age of the person with intellectual disabilities, the extent of their experience, the degree of institutionalisation, developmental level, and intellectual level. It may be important therefore to address this gap in our knowledge. Also, the development of a methodology for assessing a person's aptitude in age recognition, with norms for people with intellectual disabilities and methods of teaching age recognition, are priorities.

AUTHORS	MEDIUM	TASK	RESULTS	CEILING
Kogan et al, 1961	black/white passport photographs	9 male photos and 9 female photos to rank	progressive increases in age discrimination	5 - 6 years
Stevenson, 1967	colour film segments	3 male and 3 female photos to guess age in years	progressive increases in age discrimination	9 - 10 years
Looft, 1971	drawings	to choose older of pair from adult, adolescent, child and infant	progressive increases in age discrimination	9 - 10 years
Britton & Britton, 1969	line drawings	to choose youngest of child, adolescent, adult and older adult, then next youngest etc.	progressive increases in age discrimination	11 - 12 years
Kratochwill & Goldman, 1973	photographs	to choose older of pair from child, adolescent and middle- aged adult	progresssive increases in age discrimination	9 years

Table 1. Comparison of main studies regarding age recognition in children.

AREA	AUTHORS	RESULTS
Recognition of ages of others	Lipe-Goodson & Goebel, 1983	Progressive increases in age discrimination with age and IQ No relationship with gender
Understanding of death	Lipe-Goodson & Goebel, 1983	Improves as a function of age and IQ No relationship with gender
Recognition of age of self	Lipe-Goodson & Goebel, 1983	Relationship with IQ but inter-relationship with IQ and institutionalisation
Cues	Briggs et al., 1996	Descriptive account of training programme. Dress cues easier than facial cues or body posture.
	Hickey of Briggs et al., 1996 (personal communication)	Cues - colour of hair, wrinkles, make-up, body size, type of clothes, height, pitch of voice.
	Charman & Clare, 1992	Descriptive account of training programme. Participants said they could ask age, go by general appearance, presence of facial hair in men. Also by height and presence of rings.

Table 2. Descriptions of research studies in adults with intellectual disabilitiesrelevant to age recognition.

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AGE RECOGNITION IN ADULTS WHO HAVE LEARNING DISABILITIES

RESEARCH PROPOSAL

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Prepared in accordance with the the guidelines detailed within the Doctorate in Clinical Psychology Handbook and the Guidelines for the Forth Valley Health Board Ethics Committee (Appendix 3.1)

Supported by Central Scotland Healthcare NHS Trust and approved by The Forth Valley Health Board Ethics Committee.

AGE RECOGNITION IN ADULTS WHO HAVE LEARNING DISABILITIES

RESEARCH PROPOSAL

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SUMMARY

The ability of children to classify accurately their own ages and the ages of others has been the subject of some research. Their ability appears to improve with age and with their life experience. However, there has been very little research into the ability of adults with learning disabilities to recognise age.

Age-inappropriate behaviour shown by learning disabled adults may be related to problems in age identification of self and others, and to age, IQ level, and years of institutionalisation, and limited social ability and experience may well be important factors.

It is proposed that this research study should examine the age recognition of self and others in a group of 20 adults who have learning disabilities from within a major institution and the wider community, and investigate the relevance of the above factors.

The research study will be carried out in the area served by Central Scotland Healthcare NHS Trust.

INTRODUCTION

Knowledge of age, both of others and of self, is important for the development of appropriate social behaviour. Breaches of what is deemed to be socially acceptable behaviour may lead to very negative views of the person by other members of society, even where no criminal act is considered or carried out. For example, society has very firm views on the parameters of 'rough and tumble' play between an adult and a child. Behaviour beyond the margins of normally acceptable behaviour may be seen in a very negative light.

There has been very little research on the abilities of adults with learning disabilities to recognise or label age, but there are studies of age identification within the normal child population which yield some ideas as to how these concepts may develop. Both the child's own age and the child's experiences of other people of different ages, have been found to be related to the ability to judge the ages of others. Sheehan (1978) presented slides of men to subjects who were then asked to select the oldest of the three presented. Younger and less experienced children were not as capable of discriminating age differences as older and more experienced children. However, 'experience' here was operationalised as the number of contacts the child was reported to have had with elderly people as related by the parents. Kogan, Stephens and Shelton (1961) used passport photographs and asked children to sort them in order from the oldest to the youngest. At age four, around 50% of the children could do this but by age five, 90% of the children could do the task. Britton and Britton (1969) looked at children's ranking of line drawings of male and female figures in five age categories (child, adolescent, young adult, mature adult and older adult). The findings were that the drawings were age-ranked correctly by 4% of the pre-school sample, 29% of the second grade sample, 65% of the fourth grade sample, and 86% of the sixth grade sample. Kratochwill and Goldman (1973) used photographs of males and females in four age bands - infant, child,

adolescent and middle-aged - and found that the ability to judge age increased linearly with the subject's age. Accuracy improved from 47% at age three to 59% at age six years and 100% at age nine.

Lipe-Goodson and Goebel (1983) reported that the ability to recognise age improved with the age of the person even in learning disabled clients, although the developmental rate was slower and did not reach the same absolute level. Also, regardless of age, those clients with higher intellectual abilities demonstrated greater accuracy in the age recognition task and had a more developed concept of death. However, the length of time spent in an institution was not a strong performance indicator by itself although it did interact with other factors.

Available research therefore suggests that age discrimination is part of a developmental process which in intellectually average children is related both to age and experience.

However, the ability to know the ages of others is not necessarily closely related to the recognition of one's own age group. Guptill (1969) considered that knowing the ages of others was based on concrete, physical cues, but he considered that being able to place *oneself* in an age group was based on other cues which were not as observable - cues such as one's feelings about age and the ageing process, social ability and experience, and one's own physiological condition. If so, then it is perhaps to be expected that clients with learning disabilities may have very different views of their own ages from those of other people of the same age. For example, people with learning disabilities often have a very different set of social experiences to the norm, they have deficits in terms of social ability, and they frequently have physical difficulties (from major heart problems, epilepsy etc. to problems in motor skills to a greater or lesser degree). Also, although there have been major moves towards fuller integration and assistance in participation in aspects of life which other sections of the population

value, this has not necessarily brought their range of experiences and their quality of life to a level which the rest of the population might choose willingly. The study by Lipe-Goodson and Goebel (1983) suggested that the developmental process involved in developing an understanding of the ages of others is similar in children who are not learning disabled and in learning disabled adults, but that age perception of self was less clear cut and involved interactions between factors. For example, only 41% of the learning disabled adults correctly classified themselves, with 44% choosing younger age groups and 15% choosing older age groups. However, for women with lower intellectual abilities (defined as below the median split of their sample i.e. an Intelligence Quotient of 19-34), performance improved as a function of age but the result for men was not significant. They suggested that this related to the greater cultural value placed on youth and beauty for women. Also, success on the task was related to differences in intellectual abilities among individuals who had spent a lower percentage of their lives in institutions, but not among those who had spent a higher percentage in institutions. The authors suggested that within institutions there was less differentiation in the normal daily activities than people in the normal population experience and that this meant that there was little to which they could relate their own ageing process. Consequently, if they spent less time in institutions, the people who were more able intellectually could still learn from the environment they were in, but for those who spent a long time in institutions even the more intellectually able people became less able to notice age changes in themselves. The study, however, used line drawings and there may well be information that was lost to the subject from the selection by the artist of the salient features portrayed in the drawings. Photographs were used in the Kratochwill and Goldman (1973) study and the current proposed research study using photographs should provide further information in this area.

It would appear, therefore, that there is a paucity of research studies in this area, even looking back over several decades. Since that time there also has been much greater emphasis placed on supporting people with learning disabilities in the community rather than in large institutions. Also, in the small number of papers in this area generally, there is a distinct gap within the field of learning disabilities especially. Therefore, it would be important to evaluate the skills of the learning disabled population in recognising the ages of others and of themselves. Also it would be important to consider the relationship between ability in age recognition and factors such as intellectual ability, social maturity, age and experience of institutions. There may well be predictors of the ability having been developed or of the likelihood of it developing. It may be possible also to develop training methods to optimise ability in this area.

AIMS AND RESEARCH QUESTIONS

The proposed research study intends to investigate the ability in age recognition of self and others by adults who have learning disabilities, and the relationship of this ability to factors of age, intellectual level (IQ), social maturity and time spent in institutions.

The study will use measures of age recognition using photographs, and standardised measures of IQ and social maturity to answer the following questions:

i) is the accuracy of age group identification of others related to IQ level?

ii) is the accuracy of age group identification of others related to social maturity?

iii) is the accuracy of age group identification of others related to age of subject?

iv) is the accuracy of age group identification of others related to percentage of time spent in an institution?

v) how accurate are the subjects in identifying their own age group?

vi) is there a relationship between the subjects' ability to classify themselves accurately and their skill in accurately identifying the age group of others?

vii) where mistakes are made on self identification, do subjects err on the younger or older side of their chronological age band, and by how much?

viii) what cues may adults who have learning disabilities use to ascertain the approximate age of a person?

PLAN OF INVESTIGATION

i) SUBJECTS

A range of subjects of different ages, intellectual levels and experience of institutions will be sought. Twenty volunteer adults who may or do receive learning disability services from Central Scotland Healthcare NHS Trust will be recruited. The subject group will include clients living in the community as well as those living in the Royal Scottish National Hospital in Larbert, Stirlingshire. Subjects will be between 18 and 75 years of age.

DIAGNOSTIC CRITERIA

Subjects will be within the remit of the service for learning disabilities. This may include clients who show 'borderline' intellectual levels upon formal testing but

they will be included if they have been deemed suitable to receive the services of professional staff from within that service.

EXCLUSION CRITERIA

Excluded will be those unable to be tested using the Wechsler Adult Intelligence Scale-Revised for reasons due to suspected extremely low IQ level, a physical or neurological disability that would preclude this measure of testing IQ, extreme severity of challenging behaviour that would prevent the investigation for reasons of safety, those with a dementing illness, and those too acutely ill or medicated to participate.

CONSENT

With a parent or member of staff present, an explanation of the research project will be given to each subject with the opportunity for questions (See Subject Information Leaflet in Appendix 3.2). All subjects will sign a consent form (See Patient Consent Form in Appendix 3.3) stating that they understand the procedures and that they give their consent. Those people who are unable to write their names will be offered the opportunity to make their 'mark' instead. The staff member or parent will countersign to say that the explanation was given and that the client understood the procedure and was giving consent.

The G.P or Responsible Medical Officer will also be asked for their approval of the client's participation in the research.

ii) TESTS AND MEASURES

PRE-TEST

This brief test will check the understanding of the selection task that will be required in the age recognition measures later. It will not be in the area of age recognition. It will be a task in which the person hears a word and is asked to select the correct card for this from a choice of two.

DEMOGRAPHICS AND RELEVANT INFORMATION

Notes will be kept of age, sex and time spent in institutional care.

DEVELOPMENT OF AGE IDENTIFICATION MEASURES

Photographs will be taken showing full length figures, in colour and taken at the same distance. The people in the photographs will not be professional staff working with this client group as this might provide a variable amount of other cues.

A range of photographs will be taken covering the age-bands 0-4 years, 5-11 years, 12-15 years, 16-20 years, 21-59 years and 60-90 years. The photographs will be tested on staff from within the healthcare setting. For the final two sets of photographs (one set of males and one of females) to be used as the main age recognition measures for the study, the sets must have been arrayed correctly by 10 staff members tested consecutively with 100 % agreement. Only if there is 100% agreement may the sets be used. In the event of a full set of photographs not being achieved following the first trials, any age band(s) proving problematical will have (a) new photographs(s) included and the whole test will be carried out

once more on a different group of 10 staff and so on, until the 100% criterion is reached.

Immediately prior to the age measures, a photograph of the subject will be taken. to be used later in the Age Identification Test - Self (b) and in the Index of Adulthood - Self (d).

a) AGE IDENTIFICATION TEST - OTHERS

The photographs will be arranged in six age groups, each of two sets, one set of males, the other of females. The age groups of the photographs, as before, will be: 0-4 years, 5-11 years, 12-15 years, 16-21 years, 22-59 years, 60-90 years. The age groups are selected to utilise some legal age limits (16 and 21 years) and some convenient educational divides (pre-school being 4 years and under, primary school being up to 11 years and secondary school being up to 16 years). For the older age band, the age of 60 will be taken as a common age of retiral. These divisions should assist in later age discrimination teaching.

The subjects will be asked to point to the 'older'/ 'oldest' of two photos presented, using different combinations for each set to represent age differences of different degrees. Both terms 'older' and 'oldest' will be used because, although the comparative 'older' is grammatically correct, 'oldest' is the more frequently used colloquial term.

b) AGE IDENTIFICATION TEST - SELF

With a correct array of photographs of the same sex as the subject in front of them, with age band headings above each photograph, the headings will be read out to each subject aloud and they will be asked to select the appropriate age group for their own photograph.

c) INDEX OF ADULTHOOD - OTHERS

The same photographs in the same sets will be used as in the Age Identification Test - Others but in random order. The subject in this test will have to indicate whether the person in the photograph is an adult / 'grown-up' or a child. The terms 'adult' and 'grown-up' will be used together in case the word 'adult' by itself is not fully understood.

d) INDEX OF ADULTHOOD - SELF

The subjects will each be shown their own photograph and asked to show whether they are an adult / 'grown-up' or a child.

e) CUES

Two more descriptive tasks will then be carried out, in order to elicit cues and indicators for age discrimination. The responses will be audio-taped and transcribed verbatim.

i) The subjects will first of all be asked:

'How can you tell how old a person is? How can you work out how old they might be? What sort of things can give you an idea about how old someone is?'

ii) The complete set of photographs will then be used in random order. As each is presented the person will be asked to tell what they think this person likes to do,

where they might like to go etc. If it has not already been mentioned, the subject may be asked if the person in the photograph goes to school sometimes. After the response is complete, the examiner will say, 'I'm...xx... years old, you're...yy... years old. How old do you think this person is?" and the response will be noted.

f) WECHSLER ADULT INTELLIGENCE SCALE REVISED (WAIS-R)(Wechsler, 1981)

This measure of intellectual ability will be carried out on all subjects unless one has been administered within the last year, in which case the results of that WAIS-R will be used.

·g) VINELAND ADAPTIVE BEHAVIOR SCALES, (VABS), (Sparrow et al., 1984)

This measure assesses social and adaptive behaviour. The Communication, Daily Living Skills and Socialization Domains of the VABS will be carried out for all subjects unless carried out within the last year when those VABS results will be used.

iii) PROCEDURE

Firstly, the consent of the participants will be checked as described earlier. The ages of the subjects will be confirmed by accessing nursing or medical records, and background material will be looked at to give the number of years spent in institutions.

A photograph will be taken of each subject immediately prior to the use of the age measures using an 'instant' camera. It will be taken from the same distance as the test photographs. At the end of testing, this photograph will be given to the subject to keep.

The WAIS-R and the VABS will be administered. They will take place on a separate occasion to the age measures.

The age measures will be carried out in the order mentioned in the Measures section. Should the subjects appear to tire then the age measures may take place on two occasions with the Cues measures being postponed until another session. Early trials show that the subjects engage easily in the tasks and indeed, find them fun. Any person will be free to discontinue the procedure at any stage and there would be no penalty or disapproval for doing so.

No financial or edible incentives will be offered. Each person's photograph will, however, be given to them at the end of the assessment with thanks for their participation.

iv) SETTINGS AND EQUIPMENT

Testing will take place in a number of settings:

- 'quiet' rooms on wards within R.S.N.H.

- medical rooms within R.S.N.H.

- private and quiet rooms within the person's home or residential home

- psychology offices at R.S.N.H.

The rooms will be made as free from distractions as possible. A desk or table will be available for use.

The equipment required will be the formal measures available (WAIS-R and VABS), the newly developed measures, an 'instant' camera and an audio-tape recorder.
DESIGN

The design is essentially 'within-subjects', where a descriptive profile will be generated on the learning disabled group. It will be possible to compare results with the 100% criterion baseline from the staff sample. In order to investigate possible correlates / predictors of performance, a number of variables will be introduced as 'between-subjects' effects e.g. length of time spent in institutions, IQ, chronological age. Appropriate statistics will be selected e.g. t -tests (or non-parametric equivalent) for categorical variables, and product-moment correlations (or non-parametric equivalent) for continuous variables. Formal regression analyses may also be used.

Qualitative data will also be generated from the measures looking at cues and descriptions given by the subjects of the people in the photographs. This data will be recorded on audio-tapes and transcribed, and information noted as to what cues the subjects say they use or what they appear to notice from the photographs. This information may also be very valuable in determining an educational approach to teaching age recognition.

IMPLICATIONS

A failure to identify age accurately may result in inappropriate social behaviour such as playing with young children, the assumption by care staff, parents or the public of the person's deviant interest in young children, or actual but mistaken deviant activity with young children. It is hoped that the research will throw further light on several important issues:

• It will be useful to know whether abilities in age identification of others and age perception of self are related to chronological age, IQ, social maturity and experience of institutional life.

- Should the broader task be too difficult for many clients it may be useful to see whether a simpler choice (adult / child) aids the success rating of this task
- It is also hoped that the research may pave the way for teaching in this area and for the commencement of corrective moves to ensure that clients are encouraged where possible to learn age recognition and discrimination.
- The study may also lead to the development of a formal age discrimination task which may be useful in the field of offenders who have learning disabilities.

TIMESCALE FOR DATA COLLECTION

Development of age recognition measures - completion and criterion testing by March, 1997 Data collection - completion by October, 1997 Analysis of data - completion by March, 1998 Full study - completion and submission by August 1, 1998.

ETHICAL APPROVAL

Ethical approval for the project, and of the Subject Information Leaflet and Patient Consent Form, has been obtained from Central Scotland Healthcare NHS Trust Ethics Committee. (See Appendix 3.1)

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Major Research Project Paper

Age Recognition in Adults with Intellectual Disabilities

SHORT RUNNING TITLE : Age Recognition in Adults with Intellectual Disabilities

Prepared in accordance with guidelines for submission to 'Journal of Intellectual Disability Research' (Appendix 4.1)

Age Recognition in Adults with Intellectual Disabilities

SHORT RUNNING TITLE Age Recognition in Adults with Intellectual Disabilities

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ABSTRACT

The ability of children to classify accurately their own ages and the ages of others has been the subject of very limited research. However, the literature is largely in agreement on there being progressive increases with chronological age, though there is disagreement on the age at which the skill becomes well developed.

The processes look similar in the field of adults with intellectual disabilities although this area is extremely under-researched. Key factors may include age, the degree of institutionalisation, developmental level and IQ.

This paper presents the findings of a research study investigating the age recognition of self and others in a group of 20 intellectually disabled adults from within a major institution and the wider community. Measures of age recognition using photographs, as well as standardised measures of intellectual ability and social adaptive behaviour, were administered and correlations were found between the ability to recognise age in others and developmental age and also IQ. Success on the task of age discrimination appears to more likely if the IQ is around 60 - 65 or above and if the person shows social adaptive behaviour at an age equivalence of 8 to 9 years and over.

Also included was a task in which only the discrimination of whether the photographs were of adults or children was required, and this proved to be a simpler process for the participants.

This study also demonstrates some of the discriminative stimuli used by adults with intellectual disabilities to ascertain the approximate age of a person.

KEY WORDS

Intellectual disabilities Adult Age Recognition Discrimination

INTRODUCTION

As there has been very limited research into the age recognition of self and others in the field of intellectual disabilities, this introduction will outline what there is very briefly and will also look at the limited research in other fields, mostly from within the literature on work with children. For a more detailed literature review, the reader is directed towards Bell (1998).

Age recognition in children

The child's own age and experiences of other people of different ages, have both been found to be related to the ability to judge the ages of others (Sheehan, 1978). Kogan et al (1961) used passport photographs and found that, at age four, around 50% of the children could age-rank these successfully, rising to 90% of the children at age five. Britton and Britton (1969a) found that children could age-rank correctly in 4% of a pre-school sample, 29% of a second grade sample, 65% of a fourth grade sample, and 86% of a sixth grade sample. Kratochwill and Goldman (1973) also found progressive increases in ability at this task with age, from 47% at age three, to 59% at age six years and 100% at age nine. However, these studies used different media (such as photographic slides, passport photographs and line drawings) and the tasks required were very different.

The available research, therefore, suggests that age discrimination is part of a developmental process which, in intellectually average children, is related to both age and experience.

Age recognition in adults with intellectual disabilities

Lipe-Goodson and Goebel (1983) reported that in the field of intellectual disabilities the ability to recognise age also improves with the age of the person (including into adulthood) although the rate appears to be slower and does not reach the same absolute level. Also, regardless of age, those people with higher IQs demonstrated greater accuracy in age recognition and had a more developed concept of death. However, the time spent in an institution was not a strong performance indicator by itself though it did interact with other factors.

Knowledge of one's own age

Guptill (1969) considered that to know the ages of others, people used concrete, physical cues, but to recognise their own age they used less observable cues such as their own feelings about age and the ageing process, their social ability and experience and physiological condition. It could be expected therefore that people with intellectual disabilities may have different ideas and concepts from others, because their experiences are often very different to the norm, they frequently have physical difficulties, and they may not have the same quality of life as other groups in the population. In their study, Lipe-Goodson and Goebel (1983) found that only 41% of the intellectually disabled adults classified themselves correctly, with 44% of them choosing younger age groups and 15% choosing older age groups.

Cues used to determine age

There is almost no evaluative research on the cues used by people with intellectual disabilities to determine age, although there have been a few descriptive papers or descriptions of cues within other research.

Looft (1971) showed that the most significant cue for younger children in determining age appeared to be height but that older children made increasing use of other cues. Hurlock (1978) stated that young children use cues of size, hair colour, skin wrinkles, type of clothing or occupation, often using these cues in isolation. There are two recent papers which, although they do not evaluate the use of stated cues, do list those cues which have been mentioned in teaching sessions with adults with learning disabilities. Briggs et al (1996) report that the use of dress cues is easier than facial cues or body posture, and personal discussion with Hickey (of Briggs et al, 1996) adds other cues such as colour of hair, presence of wrinkles, use of make-up, body size, type of clothes, height, pitch of voice etc. Also, Charman and Clare (1997) report that to determine age, adults with learning disabilities say they could ask the person and they add they would go by the presence of facial hair in men. However, other unreliable indicators were also mentioned such as height (in adults) and the presence of rings.

Conclusion

The research to date on the ability of people with intellectual disabilities to recognise the ages of self and others and the relevant factors, has been extremely limited. It is important, therefore, to expand the body of knowledge and to investigate further the possible key factors of age, developmental level, IQ and years of institutionalisation. Also, there has been a major shift in emphasis from institutions to community living in the last 30 years. It may be particularly important, therefore, to understand the development of the concept of age recognition and possibly to develop ways of assisting those with intellectual disabilities to reach their potential in this area, in order to encourage appropriate social behaviour in the community.

Aims of this study

The current study investigates the abilities in the age recognition of self and others by adults who have intellectual disabilities and considers chronological age, intellectual level (IQ), social adaptive behaviour and time spent in institutions, as possible explanatory variables. The study uses newly developed measures of age recognition with photographs, and standardised measures of IQ and social behaviour to answer the following questions :

1) Is accuracy of age group identification of others related to IQ level?

2) Is accuracy of age group identification of others related to social adaptive behaviour?

3) Is accuracy of age group identification of others related to chronological age of the subject?

4) Is accuracy of age group identification of others related to time spent in an institution?

5) How accurate are adults with intellectual disabilities in identifying their own age group?

6) Is there a relationship between the person's ability to classify himself or herself accurately and the skill in identifying the age group of others?

7) Where mistakes are made in identifying own age group, are these on the younger or older side of the chronological age band?

8) What cues may be used by adults who have intellectual disabilities to ascertain the age of a person?

MATERIALS AND METHOD

Subjects

Twenty adults participated in the research study. After the Responsible Medical Officers had given approval, the subjects were approached, given information about the study and their consent sought. This was in the presence of their key worker, who also signed to show that they considered that the person understood and freely gave their consent. (Appendices 3.2 and 3.3 contain copies of the Consent Form and the Information Leaflet).

Inclusion criteria were :

a) receiving services for adults with intellectual disabilities

b) of an age between 18 and 75 years

c) successful completion of a short task based on the four training plates of the British Picture Vocabulary Test - Long Form (Dunn et al., 1982).

Exclusion criteria comprised:

a) an attention span insufficient to complete the Wechsler Adult Intelligence Scale
Revised (WAIS-R) (Wechsler, 1981).

b) a physical or neurological disability precluding the use of the WAIS-R

c) extreme challenging behaviour

d) a dementing illness

e) acute illness or a high level of medication making it difficult to participate fully.

Measures

Measures 1 to 5 were designed specifically for the purposes of this study. (A sample interview protocol is included in Appendix 4.2)

1 Age Identification Test - Others (AIT- Others)

This measure was designed to assess age discrimination and comprised 12 full length, colour photographs (Appendix 4.3 shows black and white copies of the photographs used). Images were taken at a standard distance of males and females of 0-4 years of age (pre-school), 5-11 years (primary school), 12-15 years (secondary school), 16-20 years (after school leaving age), 21-59 years (working period) and 60-90 years (retirement).

The two sets of photographs had been developed from a number of sets taken and tested on a group of staff in the same healthcare setting. Staff had been asked to age-rank the sets correctly. The two sets were reorganised until two combinations were found (one for males and one for females) which 10 staff tested consecutively were able to rank with 100% degree of accuracy.

It was considered that a similar age-ranking task would be too complex for many people with intellectual disabilities, and so the test developed for this study required the participants to be presented with only two photographs at a time, and to be asked which of the two photographs was the 'oldest' or 'older'. (Note: both terms 'oldest' and 'older' were used together, because, although 'older' is the correct term grammatically, 'oldest' is the more common term used colloquially.) The first part of the test used photographs which were three age bands apart (possible score 6, 3 male and 3 female pairs), the second part of the test used photographs which were two age bands apart (possible score 8, 4 male and 4 female pairs), and the third part used photographs which were one age band apart (possible score 10, 5 male and 5 female pairs). These raw scores were then converted to percentages of the possible score for that sub-score to give Score 1, Score 2 and Score 3 respectively, and the mean of these three as a Total Score.

2 Age Identification Test - Self (AIT-Self)

This test assessed the ability to judge one's own age band. With a correct array of photographs of the same sex as the participant, signs to show age band were placed above each and read out loud. The subject was asked to place their own photograph, taken just before the session, into the appropriate age band. Errors were noted in relation to whether these erred on the older or younger side and by how much.

3 Index of Adulthood - Others (IA-Others)

This test aimed to provide a simpler choice for participants All 12 photographs were shown, one at a time, and in random order, and the person was asked to say whether the photograph was of an adult 'grown-up' or a child. Note : Both terms adult and

'grown-up' were used together in case the former word was not known to the participant. (Possible score :12)

4 Index of Adulthood - Self (IA- Self)

This test assessed whether the participants described themselves as adults or children. The person was shown their own photograph again and asked to indicate whether or not they were an adult / 'grown-up' or child.

5 Cues

In order to determine the cues used, a semi-structured interview was developed. The interviews were audio-taped and transcribed.

i)The subjects were first of all asked 'How can you tell how old a person is? How can you work out how old they might be? What sort of things can give you an idea about how old someone is?'

Then for each of the six photographs of the same sex as the subject, given in random order, the following questions were asked :

ii)'Tell me what you can about this person?....You can make up a little story that you think would be like them....you could say what they are like and the things that they like to do, where they might like to go.' Prompts were made thereafter to request the person to expand on or to explain their comments. If it was not stated, the person was also asked 'Does this person go to school sometimes?'

iii)The interviewer then said 'I'm.....xx.....years old, you're.....yy.....years old (giving the interviewer's age and the participant's age). How old do you think this person is?'

A structure for scoring parts i) and ii) of the Interview measure was devised with a possible score of 43, based upon descriptions given by a staff sample about the age-bands in general. (See Appendix 4.4 for sample answers and scoring system).

6 Wechsler Adult Intelligence Scale - Revised (WAIS-R), (Wechsler, 1981).

This was carried out to measure IQ, unless results were available from one in the previous year.

7 Vineland Adaptive Behavior Scales, (VABS), (Sparrow et al, 1984)

The Communication, Daily Living Skills and Socialization domains were carried out as a measure of social adaptive behaviour unless these had been done in the previous year.

Procedure

Firstly, the ages, dates of birth and years of institutionalisation were all checked with the medical records. After the appropriate information had been given and consent obtained as detailed under Subjects, a full length colour photograph was taken using an 'instant' camera, taken from the same distance as the test photographs. The photograph was given to the participant at the end of the session.

The WAIS-R and the VABS were administered on a separate occasion to the age measures and measures 1 to 5 were carried out in numerical order.

The participants were tested in a quiet room in the psychology suite or in a quiet room in their place of residence or day centre.

Test-retest reliability was conducted two to three months later with a random selection of people (n = 9) being retested on Measures 1 to 4.

RESULTS

The results are broadly organised into sections with reference in brackets to the specific questions raised in the Introduction.

Descriptive information, IQ and VABS results

Participants comprised 20 adults (11 men, 9 women) ranging in age from 25 to 65 years, with a mean age of 44.6 years. Most participants now lived in the community (n = 11) although 17 people, had at some time, been institutionalised and the mean length of time of this was 25.9 years. The total sample had a mean IQ of 60.4 (S.D. = 7.6). A summary of descriptive information, including data from VABS assessments, is presented in Table 1.

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Insert Table 1 here

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In general, the functional skills of the participants were typical of the non-residential (i.e. community) population of people with intellectual disabilities which is used as a norm group within the VABS. Measures of socially adaptive behaviour and intelligence in the present study were moderately correlated (rho = 0.57, p = 0.08). This is consistent with previous research (Sparrow et al., 1984).

The relationship between age group identification and IQ level (1)

IQ was correlated with the AIT-Others (rho = 0.78, p = 0.001, two-tailed) and with the Cues measure (rho = 0.60, p = 0.005, two-tailed). However, scatterplots showed that the results at lower IQ levels were more sporadic and that around IQ 60 - 65, the participants were showing much greater ability on the AIT-Others. Table 2 presents the results of the AIT-Others according to IQ band. The results indicate that around IQ 60 - 65, people with intellectual disabilities showed an increased likelihood of being able to classify age correctly.

Insert Table 2 here

The relationship between age group identification and social adaptive behaviour (2) and other factors

Table 3 presents Spearman's correlation coefficients between the VABS (and its domains) and the AIT-Others, and between the VABS (and domains) and the Cues measure.

Further investigation by means of scatterplots reveals functional levels associated with increased likelihood of correct age discrimination. These functional levels are presented in Table 4.

Insert Tables 3 and 4 here

It seems therefore that VABS age equivalence of 8-9 years is associated with greater accuracy, and that by the functional age of 9 years, there is 100% accuracy on the AIT-Others. For the Communication domain, a similar high ability level appears at around 8 years age equivalence.

The Daily Living Skills and the Socialization domains of the VABS were not as significantly correlated with the AIT-Others, therefore no similar analysis was undertaken.

In order to look at possible predictors of the ability to discriminate age, a number of demographic details and variables were examined. Factors of chronological age and the number of years spent in an institution were not correlated with the main outcome measures (AIT-Others and Cues) and this is shown in Table 3. However, IQ

and social adaptive behaviour (VABS) were correlated and results of regression analyses demonstrated that when both of these were entered into the equation, it was IQ which had the most predictive value (Adj. $R^2 = 0.38$, p = 0.002). The VABS did not add significantly to the equation.

Skill in estimating the ages of others

In the Cues measure participants were asked to guess the actual ages of the person in each of the 6 photographs shown. Some participants gave their own age or repeated the interviewer's age (both recently heard), some gave statements such as "of an age", some appeared to give any number they could think of, and some did not reply to the question but gave another completely different response. However, even if answers were taken from those who had been completely correct on the AIT-Others and were, therefore, able to discriminate the older of two photographs shown simultaneously, *none* of these people were able to guess all the ages of the people in the 6 photographs within the years of the age-band in question.

Ability to state whether photographs were of adults or children

The IA-Others had been designed to see whether changing the task to one of deciding whether or not the photograph presented was of an adult or a child, made it an easier task for the participants. In this case, the mean score out of a possible 12 was 9.5 (range 6 - 11, S.D. = 1.3). In fact, only 3 people scored less than 9 out of 12 points on this task, their scores being 8, 8 and 6. The results, therefore, support the idea that people who have difficulty with the AIT-Others would find a task of adult / child discrimination more straightforward.

Of the 18 mistakes made on the photographs of males, 14 were in age bands 3 and 4, and of the 32 mistakes made on the photographs of females, 18 were in these age bands. This suggests that teenagers were the most difficult group to assess.

The relationship between age group identification and the age of the participants themselves (3)

As can be seen in Table 3, no significant relationship was found between the AIT-Others and the age of the participant, nor between the Cues measure and the age of the participant.

The relationship between age group identification and the time spent in institutions (4)

As shown in Table 3, no significant relationship was found between the length of time of institutionalisation and either the AIT-Others or the Cues measure.

Identification of own place within an age group (5 and 7) and the relationship of this with the ability to do so for others (6)

Table 5 shows the relationships between the participants' abilities to state their own ages correctly and to put their own photographs into the correct age band, and their abilities in discriminating the ages of others on both the AIT-Others measure and the Cues measure.

Insert Table 5 here

Although 13 people could state their age correctly, only 8 people were able to match their own photograph to the appropriate age-band photograph. When these two factors were taken together, 7 people could do *both* tasks correctly. If those who were able to do *both* of these tasks correctly were compared to the group of people who could do only one *or* other task, *or* neither task, (using the Mann-Whitney U test), the results were significant at p = 0.004 (two-tailed) for the AIT-Others measure. This factor (of being able to state own age *and* identify the correct age-band for own photograph) was then re-entered into the regression analysis and it explained all of the variance (Adj. $R^2 = 1.00$). The results show, therefore, that the best way to predict whether or not a person can discriminate age in others is by assessing whether or not they know their own age *as well as* whether or not they can place their own photograph within the appropriate age band.

Accuracy of understanding of own age band (7)

Of the 20 participants, 8 placed their photograph in the correct age band. No person classified themselves as older than their actual age band but all mistakes erred on the younger side, some quite considerably.

Five people placed themselves in an age band which was one age band younger, 3 people placed themselves in an age band which was two age bands younger and 4 people placed themselves in an age band which was three age bands younger than their actual age group. All participants, however, were in the fifth of the age bands according to their chronological age, thereby limiting the choice of older age bands.

Analysis of the qualitative material (8)

The information used by people in the interview part of the procedure yielded a variety of discriminative stimuli by which they appeared to determine age groups. When asked to say how they would tell how old a person was, answers were, in the main, minimal. Eight people gave answers stating or showing that they did not know how to answer this. Two people made comments on 'faces' but without further elaboration. These two people may well have been considering the presence or absence of facial lines and wrinkles but they may not have had the expressive communication to expand upon their answer. Of the 10 other people, clues included comments on grey or white hair, clothes, wrinkles, 'rough' skin, height, make-up,

jewellery, walking sticks and wheelchairs. Regarding make-up and jewellery, the gentleman who mentioned these equated the wearing of make-up with being 'old' and the wearing of jewellery as meaning that the person was over 16 years of age. At least 2 people felt that grey or white hair was by itself an accurate and necessary sign of old age, and 3 people seemed to equate increasing height with increasing age with no mention of this 'rule' being applicable, in the main, in the childhood years. (See Appendix 4.5 for an extract from one of the transcripts)

There was also a significant relationship between the Cues measure and the AIT-Others (rho = 0.69, p = 0.001, two-tailed).

Reliability of the main new measures of age

In order to assess the test-retest reliability of the AIT-Others and the IA-Others, these measures were repeated at follow-up on 9 participants, chosen by their ready availability for retesting. For the AIT-Others, the relationship was significant (rho = 0.84, one-tailed, p = 0.003). However, for the IA-Others, this was not significant (rho = 0.33, one-tailed, p = 0.19).

DISCUSSION

Results therefore, show that most adults who have intellectual disabilities do not have the same understanding of age as the normal population. The use of age described in terms of years was of little meaning to most people in this study even though many of them knew their own age by rote and all but one knew that they were adult. It might be that many of the participants may not be able to count very high in numbers, may not have one-to-one number correspondence, and may be unable to add up small amounts, and the use, therefore, of a number of years to explain the age of a person, may not have much meaning. Instead, the other tasks in this current study, of assessing the older of a pair of photographs, of saying whether someone is a child or an adult, and of describing what a person may like to do, may have greater meaning.

With regard to IQ level, this study supports the view that those with higher IQs demonstrated greater ability in age recognition (Lipe-Goodson, 1983) but it goes farther, to suggest that around IQ 60 there is much increased ability in age recognition. Further research would be required to tease out this relationship more. Chronological age was not a relevant factor in the present study, as it had been in the Lipe-Goodson & Goebel study (1983).

The findings of this study also support previous research that developmental age may be important (Kogan et al, 1961; Sheehan, 1978; Britton & Britton, 1969; Kratochwill & Goldman, 1973; Stephens & Shelton, 1961). Indeed, the current study suggests that skills in this area for people with intellectual disabilities improve as age equivalence in social adaptive behaviour increases, with a level of nine years being the stage at which it may be expected that the skill has reached its ceiling. The degree of institutionalisation was not seen to be important in this study, whereas it had been in the Lipe-Goodson study (1983). This may reflect the differences in the last 15 years in the community integration of people who have intellectual disabilities and the steps made towards the closures of the large institutions. Even where these institutions remain, more is known about the damage done by institutionalisation and practices have changed considerably, placing more emphasis on community participation and in the acquisition of community skills. Although there were difficulties for most people in discriminating who is the older of two people, when the task was simplified to one requiring the person to decide whether or not the person was an adult or a child, the results showed that more people with intellectual disabilities could discriminate at this gross level. This is, in itself, a useful finding for teaching purposes. Although there were mistakes made on this task, those mistakes were generally made about people within the teenage years, a difficult discrimination task for publicans, licensed staff etc. Without norms for

groups in the general population, it is difficult to see whether or not results on this 'simplified' test are on a par with the normal population. It is suggested that this is addressed in the future. Possible other norm groups for comparison would include publicans, police officers and teachers.

This study, also, supports the previous research in the field of intellectual disabilities (Lipe-Goodson & Goebel, 1983) and in the general population (Bennet, 1976; Kastenbaum et al, 1972; Rosow, 1977) that most people would select the younger side of their real age as that age to which they feel they belong. However, in this study, these younger age bands were often a considerable number of years away from the person's actual age. This may support the opinion of Lipe-Goodson and Goebel (1983) that many people with intellectual disabilities have lifestyles that do not change as they age and therefore they are more likely to identify with a younger age band than the general population.

The measure developed to assess age discrimination of others (the AIT-Others) was shown to be reliable on retesting. However, the 9 people retested had been chosen purely on the grounds of their easy availability and the results later showed that only 2 people in the retest group had IQs over 65 and only 5 had IQs over 60. In addition, only 2 people had an age equivalence on the total VABS of over 8 years, with none over 9 years, and only 1 had an age equivalence over 9 years in the Communication Domain. Also, of the people retested, only 2 had been able to give their own age correctly *and* place their own photograph into the appropriate age band. This information shows that the retest group of 20 people been retested, then the results may well have shown increased reliability. In order to refine the results from this study, further testing is required with groups of people falling into different IQ bands and functional age equivalence bands.

The test of discrimination of whether the photograph was of an adult or a child (the IA-Others) was *not* shown to be reliable on retesting. However, this measure used photographs developed for the measure discussed above, and the test itself had not

been tried on the healthcare workers. Consequently, the results in the present study are not comparable with the normal population until other norm groups have been assessed. If this measure is found to be very difficult for the normal population, especially for some photographs of teenagers, then the results of the task in this study need not be consistent, reflecting the difficulties inherent in the task. Indeed, some age groups are very difficult for the normal population and, for example, passport-style identification cards for teenagers are now commonplace for public houses and licensed premises. It may be that, faced with such difficult decisions, people in *all* populations could vary these answers in this test when retested over time, resulting in the unreliability of the test itself, and this needs to be taken into account when assessing the results.

One important aspect which has not been measured by most researchers but which has been written about descriptively by some, is the consideration of the cues used by adults with learning disabilities to determine age bands (Briggs et al, 1996; Charman & Clare, 1992). This study gives an indication of how this might be made more measurable and it supports the evidence to date that many people with learning disabilities use unreliable cues such as the presence of jewellery and the use of walking aids, as well as the main measure of 'size' or height which also is not necessarily very reliable.

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		u	mean	range	S.D.
AGE (years)	all participants	20	44.6	25-65	13.5
	men	11	44.2	25-65	14.8
	woman	6	45.0	29-63	12.7
I0	all participants	20	60.4	50-74	7.6
	men	11	59.8	50-75	8.2
	women	6	61.1	50-70	7.3
Time in	all participants	17	25.9	1-55	17.1
Institution	men	6	22.5	1-53	17.5
	women	8	29.8	5-55	16.8
	never in institution	3	n/a	n/a	n/a
		n			n
Current	Living in all particil	pants 9	Living in	all partici	ipants 11
Living	Institution men	3	Commur	ity men	8
Situation	women	9	Marine Contraction of	women	3
	VABS domain	mean	range		S.D.
VABS	Communication	5 years 10 months	2 years 7 months -	9 years 10 months	2 years 0 months
Age	Daily Living Skills	9 years 0 months	5 years 1 month - 1	5 years 9 months	2 years 1 month
Equivalence	Socialization	7 years 3 months	3 years 9 months -	11 years 3 months	3 years 0 months

Table 1. Descriptive information in the sample (n=20), comprising data on age, IQ (WAIS-R), time in institutions, social adaptive age equivalence (VABS), and current living situation.

IQ band	n in subgroup	n of this sub-group with AIT-Others score of 90 - 100			
<54	6	0			
<u>≥</u> 55	14	9			
<u>></u> 60	11	9			
<u>≥</u> 65	6	6			

Table 2. Bands of IQ scores (from WAIS-R) with the number of participants in each of these bands and the numbers of these with scores on Age Identification Test-Others of 90-100. (Total n = 20).

(Note that numbers in sub-groups are not mutually exclusive e.g. some people with $IQs \ge 55$ will also be in with the subgroup of those with $IQs \ge 60$ etc.)

	AIT-Others	Cues
Chronological age	rho =04	rho =20
	p = 0.87	p = 0.39
Years in institutions	rho =24	rho =22
	p = 0.31	p = 0.35
IQ	rho = 0.78	rho = 0.60
	p = 0.001 ***	p = 0.005 **
VABS Total	rho = 0.60	rho = 0.70
	p = 0.005 **	p = 0.001 ***
VABS Communication	rho = 0.67	rho = 0.66
	p = 0.001 ***	p = 0.001 ***
VABS Daily Living Skills	rho = 0.50	rho = 0.65
	p = 0.024 *	p = 0.002 **
VABS Socialization	rho = 0.45	rho = 0.38
	p = 0.045 *	p = 0.098

Table 3. Spearman's rho correlations and levels of significance (two-tailed) between measures of age recognition of other people and VABS results, IQ, years spent in institutions, and chronological age ($p \le 0.05^*$, $p \le 0.01^{**}$, $p \le 0.001^{***}$)

Age equivalence on VABS	n in this sub-group	n of this sub-group with AIT-Others score of 90-100	
Total VABS < 7 years	7	1	
Total VABS \geq 7 years	13	8	
Total VABS \geq 8 years	6	5	
Total VABS \geq 9 years	3	3	
Total VABS ≥ 10 years	2	2	
Communication < 7 years	14	4	
Communication \geq 7 years	6	5	
Communication ≥ 8 years	4	4	

Table 4. Bands of VABS age equivalence scores (Total and Communication Subdomain) with the numbers in these bands (total n = 20) and the numbers of these with Age Identification Test-Others scores of 90-100.

(Note that numbers in subgroups are not mutually exclusive e.g. some people with VABS scores of \geq 7 years will also be in the subgroup of those with VABS scores of \geq 8 years etc.)

Task	AIT -	Others	Mann-Whitney	Cues		Mann-Whitney
	mean	S.D.	level of significance	mean	S.D.	level of significance
States own age correctly (n = 13)	88.10	13.67	0.0001	15.00	2.61	0.0464
Unable to state own age correctly (n = 7)	55.04	26.78	p=0.022*	11.14	4.95	p = 0.046*
Matches own photograph to correct band (n = 8)	90.52	17.83	0.021*	15.13	3.27	0.175
Unable to match own photograph to correct band $(n = 12)$	67.20	24.65	p = 0.021*	12.67	4.19	p = 0.175
Able to state own age and match photograph to correct band (n = 7)	96.11	8.91		16.00	2.3	1
Unable to state own age and match photograph to correct band (n = 13)	e 55.65	23.33	p = 0.004*** -	12.38	4.1	p = 0.047*

Table 5. Potential predictors of age recognition ability as measured by AIT-Others and Cues. Data are presented with mean, standard deviation and results of Mann-Whitney U tests (two-tailed) ($p \le 0.05^*$, $p \le 0.01^{**}$, $p \le 0.005^{***}$)

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Single Clinical Research Study I



Woman with Down's Syndrome

Prepared in accordance with guidelines for submission to the 'British Journal of Learning Disabilities' (Appendix 5.1)

Selective Mutism:

Diagnosis and Treatment in a Woman with Down's Syndrome

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SUMMARY

The case concerns a woman of 36 years of age with Down's Syndrome who had shown selective mutism for over 14 years, although this had become almost complete mutism for the last 8 years. The aim was to reinforce communication and to gradually increase the number of words whispered or spoken in the presence of the psychologist.

The treatment used non-aversive behavioural methods and developed response initiation procedures to the therapist and then generalisation of vocalisations to other people in other environments. The treatment was carried out three times a week for about two months with rapid success, and the woman's quality of life at home and her interactions at her Training Centre improved markedly. Intervention continues with a speech and language therapist in the lead role and with the psychologist providing maintenance and support.

BACKGROUND

History and definition

In 1877 Kussmal (reported in Browne, Wilson & Laybourne, 1963) described physically normal children who developed mutism in specific situations as having 'aphasia voluntaria'. Later, Tramer (1934) used the term 'elective mutism', believing that these children were choosing not to speak. The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) (American Psychiatric Association, 1994) uses the term 'selective mutism', implying that these children do not speak in 'select' situations. The essential feature described is 'the persistent failure to speak in specific social situations (e.g. school with playmates) where speaking is expected, despite speaking in other situations'. However, difficulties in diagnosis are confounded by reports from several authors regarding the comorbidity of selective mutism with both speech and language problems (Wright, 1968; Kolvin & Fundudis, 1981; Wilkins, 1985) and with a diagnosis of learning disabilities (Klin & Volkmar, 1993), and by the high frequency of communication disorders, including the absence of speech, in people with learning disabilities (Bott, Farmer & Rohde, 1997).

As described above, selective mutism refers to the failure to speak in *specific* social situations despite speaking in other situations. However, there are reports in the literature of cases which do not meet these criteria. Chetnik (1973) reported a case study of a child with almost no verbal interactions to parents, relatives, adults or peers in either school or home environments. Similarly, other cases were reported by Reed (1963) and by Straughan (1968). In 1987 Paniagua and Saeed introduced the term 'progressive mutism' to describe a child who met all the criteria for elective mutism, except that the child talked to nobody, with this having happened progressively over time, despite the absence of neurological and biological variables.

There is also an important distinction between elective mutism which is transient and that which persists. Transient selective mutism is reported more commonly and generally applies to children of around 5 to 7 years of age around the commencement of their schooling (Brown & Lloyd, 1975 ; Kolvin & Fundudis, 1981). However, persistent selective mutism is reported to occur only in 0.03% to 0.06% of children (Brown & Lloyd, 1975) or 0.08% of children (Fundudis et al., 1979). Also, although most speech and language disorders are more common in boys than in girls (Baker & Cantwell, 1991), a higher incidence of selective mutism is reported in girls than in boys, with ratios given of 2.4:1 (Wright, 1968) or 2:1 (Wilkins, 1985).

Aetiology

Selective mutism has been explained as a response to family difficulties especially those with over-protective or domineering mothers, or strict and remote fathers (Browne et al., 1963; Pustrom & Speers, 1964; Meyers, 1984), as evidence of an unresolved psychodynamic conflict (Elson et al., 1965) or as a reaction to trauma (MacGregor et al., 1994). There have also been comparisons made between this group and socially phobic adults (Black & Uhde, 1992). The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994) reports common associated features of 'shyness, fear of social embarrassment, social isolation and withdrawal, clinging, compulsive traits, negativism, temper tantrums, or controlling or oppositional behavior particularly at home'. Kolvin and Fundudis (1981) found 'almost invariably a streak of negativism and poor malleability both at school and at home.'
Prognosis

Selective mutism is often reported to be 'difficult to treat' (Watson and Kramer, 1992) and 'intractable' (reported in Dow et al., 1995), and prognosis is said to be 'poor' (Afnan and Carr, 1989), although a few behavioural studies have obtained some positive results in children (Norman and Broman, 1970; Lipton, 1980). However, the majority of research studies relate to children within the normal population and little is written about treatment for adults who have learning disabilities.

Assessment

For children within the normal intellectual range who show selective mutism, Dow et al. (1995) suggest a comprehensive assessment including a developmental and medical history, details of neurological insults, developmental delays, academic ability, neuropsychological deficits and a family history. This includes an assessment of hearing, for studies have shown that even a very mild hearing impairment can have a negative effect on speech and language development (Fundudis et al., 1979). They also recommend the inclusion of details of speech and language ability and of verbal and non-verbal communication over a variety of situations, including pragmatic skills such as turn-taking in conversation and any speech production problems.

It should be noted here that high rates of hearing impairments are reported for people with Down's Syndrome and also a high rate of problems with chronic ear discharge (Brooks et al., 1972; Cunningham & McArthur, 1981; Lavis, 1997) and these areas are, therefore, of great relevance.

Treatment

Most treatment approaches have been based on behavioural interventions and these are reviewed in Labbe and Williamson (1984). Their article also suggests treatment strategies based upon five different outcomes of the assessment. The first is for reluctant speech, the second for when the child speaks to at least one person in all situations, the third if the child speaks to most persons but only in one environment and the fourth if the child speaks to only one or a few persons in only one environment. The fifth type of assessment outcome they report to be the most challenging case and this is when the child speaks to no-one who is available for the treatment programme. Here they suggest that response initiation procedures have to be established in the presence of at least one person and then stimulus fading procedures used to generalise the speech to other environments and with other people. Finally they advise reinforcer fading once a stable rate of speaking has been established across all environments. This approach is similar to that advocated by Paniagua and Saeed (1988) who suggest that the first stage of treatment for 'progressive mutism' should be to encourage 'selective mutism' (i.e. speech or verbalisations in the presence of one or more people such as therapists or parents), prior to aiming for the long term goal of speech with most people across a variety of environments.

CASE HISTORY

This case concerns a woman of 36 years of age with Down's Syndrome who was almost completely mute with everyone in all situations, despite having been described as fully verbal 14 years ago. At referral, she was reported only to speak a few words quietly to herself when alone.

She lived with her father (her mother having died a year ago), the second child of eight children in the family. The family was very close and although all but one

sibling had left home, they lived nearby and they all visited several times a week and socialised together and with members of the extended family. The father was working but, with help from his family, he managed to suit his hours around the client's day. She attended a local Resource Centre five days a week.

There was no reported family history of speech and language difficulties, deafness or psychological problems. Maternal delivery was straightforward. As a child, she was reported to have developed within the milestones of those with Down's Syndrome and to have had what the family perceived as 'normal' speech for those with Down's Syndrome. She was said to have always been determined to have things her own way.

At the Resource Centre, she was reported to speak to no-one, to speak to herself only on extremely rare occasions, to be particularly wary of men and to be concerned about noise. In addition, she was said to join in no activities whatsoever, not even watching others, to sit only in one place in the very large dining room for the duration of her time at the Centre (with rare exceptions), and to obsessively turn over her 'papers'. These were two sets of post-card sized pieces of paper on which someone else had written names and addresses (some spurious) of people she knew. Very occasionally she would set the table if the implements were left nearby, and rarely, she might sit elsewhere. She wore a number of rings on her fingers. Occasionally she would become very distressed for no apparent reason and would sit under her table or repeatedly bang doors. No staff member at the Centre had been there long enough to recall her ever speaking.

Some 14 years ago, a descriptive report of her general abilities was made by a psychologist and this mentioned that she was then reluctant to speak, required lots of prompts, spoke only in short phrases and did so in a 'slow, hoarse whisper which probably irritates her throat'. The report also commented that she seemed to be a different person at home, looking very happy in photographs and socialising.

The family related that her speech at home diminished gradually until about eight years ago when it ceased all together. One sister also mentioned that she believed she had had some teasing in the past for her unusual voice. For the last eight years they had only heard her speak a few words occasionally to herself in private, and sometimes had heard her say the name of her youngest sister's boyfriend. In the last year she had also withdrawn socially at home and went straight to her bedroom on arriving home. She would stay there almost all of the time, watching T.V. and videos.

Clinical psychological formulation

The diagnostic criteria in DSM-IV for 'selective mutism' are as follows :

A. Consistent failure to speak in specific social situations (in which there is an expectation for speaking, e.g. at school) despite speaking in other situations.

B. The disturbance interferes with educational or occupational achievement or with social communication.

C. The duration of the disturbance is at least 1 month (not limited to the first month of school.)

D. The failure to speak is not due to a lack of knowledge of, or comfort with, the spoken language required in the social situation.

E. The disturbance is not better accounted for by a Communication Disorder (e.g. stuttering) and does not occur exclusively during the course of a pervasive Developmental disorder, Schizophrenia, or other Psychotic Disorder.

The client appeared to meet the criteria in DSM-IV for Selective Mutism except that she no longer spoke in any social situation, other than a few words alone to herself or the name of her sister's boyfriend. In this case, the term mooted by Paniagua and Saeed (1988) of 'progressive mutism', would seem to be more appropriate as it describes a progression from selective mutism to almost complete mutism.

It is difficult to see how the problem first started, however. The description of associated traits mentioned in DSM-IV certainly describes aspects that may apply in this case. For instance, she may have been shy at the Centre 14 years ago and she could possibly have been embarrassed at the sound of her voice, or perhaps been teased for it. Home seemed a happy and friendly place although the family tended to do things for her, with good intentions, rather than encouraging her to develop her independence. Also, people around her, at home and at the Centre, appeared to accept her mutism and to cater for this, but to have no expectation of speech, which has perhaps served to maintain and deepen the problem in the past eight to fourteen years.

There appeared, therefore, to be two working hypotheses for her gradual withdrawal of the use of language. Firstly, there was evidence of her family's good intentions which may have robbed her of the initiative to speak by anticipating her needs and they may have gradually reduced reinforcement for speech. Her reported stubbornness may have been her response to this in order to increase her level of control over her environment. This hypothesis would consider her response to be similar to those selectively mute children in families with over-protective or domineering mothers or strict and remote fathers (Browne et al., 1963; Pustrom & Speers, 1964; Meyers, 1984) and her response would also explain her reputation for being stubborn, which had been found in almost all of the cases of children investigated by Kolvin and Fundudis (1981). Secondly, there may have been incidents with other trainees at the Centre or with the public which caused her to be so embarrassed by her voice that she may have become phobic about her speech or developed social phobia. Some teasing had been mentioned by one sister. This would accord with the comparisons made with socially phobic adults (Black & Uhde, 1992).

Treatment was based upon the first hypothesis, and started with the premise that she wished to communicate but that her initiative to do so had decreased over time. Should factors of embarrassment or social phobia have become apparent, then this would have signalled a change in treatment. Treatment followed a non-aversive and constructional approach (Cullen et al. 1981; LaVigna & Donnellan, 1986), which enables the person to achieve what they want in an acceptable and rewarding way.

Due to her extreme problem, it was not possible to determine whether or not there was currently a hearing or a voice production problem or whether the mutism was alongside another simultaneous communication disorder.

The case was discussed with professional colleagues in Speech and Language Therapy and a collaborative, staged approach was agreed. A psychological approach was felt to be required initially, but as soon as vocalisations and interactions were re-established, joint work would begin to assess hearing and voice production problems. Also, once vocalisations had increased with some generalisation to other staff and situations, the lead professional role would pass to Speech and Language with Psychology in a supporting and maintenance role. The main research question was whether or not such a degree of selective mutism could be treated given its severity and long duration.

STAGES OF INTERVENTION

Originally, treatment was planned with the overall aim of encouraging *any* vocalisations. However, progress was made extremely quickly and, therefore, an intermediate stage (Stage 2 below) was added during the intervention period with the aim of increasing the use of spoken in relation to whispered sounds.

Stage 1. Overall aim:

To encourage *any* vocalisations. This would include spoken and whispered words, whether intelligible or not, laughter, other sounds such as 'oohs' and 'aahs' etc. The number of sessions in this stage was determined by the amount and speed of progress. Once a consistent use of vocalisation was achieved then a reassessment of aims was made for the second stage.

Stage 2. Overall aim:

a) After discussion with the Speech and Language Therapist, the aim of this stage was to increase the emphasis on spoken as opposed to whispered sounds, whilst maintaining a high number of sounds made generally.

b) To extend the range of people spoken to and situations.

Stage 3. Overall aim:

To transfer the case to Speech and Language Therapy as the lead discipline, and to support that therapist, to assist in maintaining progress and to increase generalisation to other people and situations.

ASSESSMENT MEASURES

Baseline

a) A standard measure of social and adaptive behaviour, the Vineland Adaptive Behavior Scales, (Sparrow et al., 1984) was used. b) An assistant psychologist assessed the client's use of language and communication, and her social interaction over 3 one hour observation periods, taken at random within the Centre.

End of Stage 1 and Stage 2

The observations were repeated over 3 one hour observation periods, taken at random.

Continuous assessment

During each session, all activities and games were noted. Details were kept of any sound productions. This included spoken and whispered, intelligible or unintelligible 'words', 'oohs', 'aahs' and peals of laughter. Details of eye contact, quality of sound, social behaviour, ad hoc assessment of hearing and content of 'speech' were also noted.

End of Stage 3

It is anticipated that a Clinical Psychologist will assist in measures chosen by the Speech and Language Therapist to assess progress at this stage.

METHOD

Sessions were arranged three times weekly in the Centre between the psychologist and the client, with a quiet room booked for use if the client could be encouraged to go there.

A fixed ratio schedule (1-1) of contingent praise was used along with other reinforcement enjoyed by the client. Initially, these were songs by Abba, played

on a personal stereo and the giving of tiny pieces of chocolate. The ratio moved rapidly over the first few sessions to be intermittent, although the therapist's pleasure in the client's communication was always shown.

To gain the client's attention at the first appointment, the therapist sat next to the client who was turning over her 'papers' and matched this activity by turning over a set of cards with colour pictures on them. The client noticed this and was offered one and a game was built up similar to 'snap'.

Gradually other activities were introduced, such as the use of nail varnish and make-up, party squeakers and poppers, picture cards (for games of snap, pelmanism and matching games), large colour dominoes, picture cards of everyday items, 'guess-the-sound' tapes, small musical instruments etc. A small sticker was chosen by the client at the end of every session to go on her spectacle case.

RESULTS

Age equivalence

The domains of the VABS can be measured in terms of age equivalence. For the Communication, Daily Living Skills and Socialization Domains of the VABS, the results were as in Table 1. Extremely low scores on the domains of Communication and Socialization are noted although a relatively high strength is seen in the area of Daily Living Skills.

The scores on the domains of the VABS may be compared to norm groups. Comparisons between this client's performance and two norm groups often used in the field of learning disabilities are given in Table 2. The norm groups are for ambulant clients living in a residential facility and clients in the community in non-residential facilities. These norm groups are usually taken to reflect living in a major institution and living in small units in the community, respectively.

Insert Table 1 here

The client's scores are low relative to community norms and are more similar to the institutional norms.

Sound productions

Figures 1 and 2 show the client's sound production over the treatment sessions in Stages 1 and 2. They show a dramatic improvement in the number of 'words' made, whether intelligible or not, and whether spoken or whispered. In Sessions 9 and 15, the client had extremely bad colds which probably inhibited these and the following sessions.

Insert Figures 1 and 2

Table 2 shows the results of the assessment measures taken by the assistant psychologist in 3 one-hour observation periods chosen at random. Unfortunately, the 3 periods at the end of Stage 2 did not coincide with groups happening at the Centre and consequently the client's interactions or otherwise with a group could not be noted at this stage. However, it can be seen that the total number of spoken and whispered intelligible words (taken together) was maintained from the end of Stage 1 to the end of Stage 2, as was her evident enjoyment (noted from the voiced laughter), and there was a big increase in the total number of spoken and whispered unintelligible words in this time.

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Insert Table 2 here

Over 22 sessions there was also a number of examples outside sessions which illustrated progress. (See Table 3.)

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Insert Table 3 here

Hearing

Early sessions showed that the client did appear to hear and occasionally to respond to some language. However, she was also very skilled in the understanding of non-verbal behaviour and, without a formal hearing test, it was difficult to be sure whether or not she had a major hearing problem. Also, there may have been difficulties at specific frequencies, or intermittent difficulties, such as tinnitus.

Voice Production

Early sounds made were rather gruff, deep and coarse sounding, and occasionally high and squeaky. This may have reflected the long duration of lack of use or a voice production difficulty. Assessment of this continued after Stage 2 with the Speech and Language Therapist.

Effect of sounds made on client

When the client made noises, there were no signs of embarrassment. Instead, she looked surprised and then delighted, often quietly chortling with apparent glee, occasionally roaring with laughter.

Content of language and sounds

The content of the sessions was interesting. Initially, the language used was considered to be self-reflection, a talking to herself. For instance, as she had only spoken to herself for years, her use of the word 'dog' on being shown a picture of one was thought to show her speaking to herself. However, by Stage 2 it seemed as if language with the therapist was used mainly with a nominative function and only rarely with a communicative function. There were, however, a few indications of communication by speech and signs in and out of sessions. Also, she seemed at first reluctant to choose an activity from a selection and although this reluctance disappeared, the 'choice' was usually the nearest, the one touched by the therapist etc.

Eye contact

Eye contact was fleeting and seemingly accidental in the baseline assessment and in the first few sessions. By Session 22, on some occasions, she would give eye contact of a few seconds.

Social behaviour

There was a gradual and then a rapid change in her social behaviour. Some examples may be seen in Table 3. She began joining in other groups in the Centre during Stage 1 and then interacting with them, occasionally initiating social contact with others. This began to generalise to the home situation towards the end of Stage 2. She was also described as being very much happier by the end of Stage 1, with wide smiles and laughter being a common feature by the end of Stage 2. She had also by then, begun to participate more in tasks set at the Centre such as laying tables, carrying things for staff, tidying out cupboards, going out on outings with groups etc.

DISCUSSION

Despite the severity of this specific problem, its long-term duration and the concomitant learning disabilities, progress was swift. Treatment had followed the Labbe and Williamson (1984) and the Paniagua and Saeed (1988) models successfully and had encouraged the change from almost complete mutism to selective mutism with the therapist in a variety of room settings. It had then extended the number of people and situations in which language was used. At the end of this period it then became possible to begin to assess other areas, such as hearing and voice production, which had previously been inaccessible to clear measurement. The speedy results and the lack of any apparent embarrassment at the sound of her voice supported the chosen hypothesis.

However, in terms of replication by others wishing to work with clients who are selectively mute, the content of sessions was specific to this client and were also quite varied. Sessions depended upon collaboration between the client and the therapist and upon the therapeutic alliance which was gradually built up. The content of sessions had to be flexible to cope with the client's colds and moods, and with other factors such as events in the Centre, noise levels there, the availability of a private room at the Centre, and interruptions to the sessions by other trainees.

Also, the intervention was based upon sessions with the Clinical Psychologist three times a week for an hour over several months and continuing work is based on weekly sessions by the Speech and Language Therapist supported by two other sessions weekly from a Psychologist for maintenance and support. Whether or not the progress shown here could be replicated if carried out less intensively is not known. There is an element which could be improved for future studies. The measures used in this case study were based upon the almost complete lack of communication seen in the baseline period and they counted only words and sounds. Once some speech is established, other measures to do with complexity and relevance could be introduced. For example, in this case study, a phrase such as 'that's a wee dog' counted as 4 words and yet 'baby, baby, baby, baby' counted as 4 also. The latter appeared to be a phrase used to indicate happiness and it was often used without reference to a baby. A measure of the function of speech could have been introduced. For example, 'pardon' was said following burping, 'dog' in response to a picture of a dog, 'baby' because she was happy, 'new ring' said to a staff member wearing a new ring, and 'Can I have a drink of tea, please?' to request a drink, and yet all these examples relate to different functions of speech.

However, the success of this intervention does show that even in cases of extreme selective mutism with a duration of many years, progress can be made.

ACKNOWLEDGEMENTS

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TABLES AND FIGURES

Age equivalence of client on three domains of VABS				
Communication	0 years 11 months			
Daily Living Skills	4 years 11 months			
Socialization	0 years 11 months			
Client' VABS	s VABS scores relative to Norm group of ambulatory clients in residential facility	two sets of norms Norm group of clients in non-residential facility		
Communication				
Receptive	below average	below average		
Expressive	average	below average		
Written	average	below average		
Daily Living Skills				
Personal	average	below average		
Domestic	above average	below average		
Community	average	below average		
Socialization				
Interpersonal	below average	below average		
interpersonal				
Play and Leisure Time	average	below average		

Table 1. Age equivalence relative to normal population of VABS of client's

scores and comparisons with two norm groups.

Activity measured	Baseline	End of Stage 1	End of Stage 2
Alone, not in group	100%	8%	n/a
In group	0%	92%	n/a
Doing same as group	0%	100%	n/a
Interaction with group	0%	36%	n/a
Number of words spoken, intelligible	0	6	0
Number of 'words' spoken, unintelligible	0	15	10
Number of words whispered, intelligible	0	1	7
Number of 'words', whispered unintelligible	0	22	77
Voiced laughter	0	7	8

Table 2. Data at Baseline and end of Stages 1 and 2 for a variety of activities measured by behavioural observation over 3 random one-hour periods on each occasion.

SESSION	ILLUSTRATIVE EXAMPLES OF PROGRESS
Session 6	a)Not in 'usual' spot in diningroom as therapist arrived, but
	in group, painting, as others in group
	b)Aide on bus heard her 'talking' to another trainee, words
	not heard, but said to be vocalising
Session 8	Now reported to be joining in groups more and more
Session 16	Reported to have said 'ring' (spoken) to Day Centre Officer
Session 17	Smiled at other trainee en route to session, offered her
	hand and then continued to hold it as a friend might
Session 18	Said to Day Centre Officer, 'Can I have a cup of tea,
	please?' The reply was, 'Who's it for?' and she replied,
	'For me!'
Session 20	Father reported client no longer being isolated in own
	room at home, but enjoying being in the living room with
	him and other members of the family and friends

Table 3. Illustrative examples of change as sessions progressed.









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Single Clinical Case Research Study II

Assessment of Age Recognition Skills

and Treatment Failure in a Gentleman with Learning Disabilities :

A Case Study

Prepared in accordance with guidelines for submission to the 'British Journal of Learning Disabilities' (Appendix 6.1)

Assessment of Age Recognition Skills

and Treatment Failure in a Gentleman with Learning Disabilities :

A Case Study

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SUMMARY

A man of 43 years of age, who has mild learning disabilities, was referred after several contacts with the law when he was seen in the street talking to children who were unknown to him. Some staff members feared that he had a sexual interest in children, and others considered that the behaviour was innocent, reflecting his friendly nature, but that it was a behaviour which was misinterpreted by others.

This case study charts the assessment of his difficulties and his abilities over a wide range of relevant areas and the reassessment following an intensive period one-to-one training on age recognition skills. Although the training was unsuccessful, the measures used assisted in a detailed assessment and clear instructions to care staff.

BACKGROUND

As a review of the literature illustrates (Bell, 1998a), there is a great paucity of research in the area of age recognition in people who have learning disabilities. What there is, suggests concept development similar to that seen in children improving with chronological age and life experience.

In children, there is a wide range reported of the ages by which the concept is normally developed :- 5 - 6 years (Kogan et al., 1961), 9 - 10 years (Stevenson et al., 1967; Looft, 1971; Kratochwill & Goldman, 1973), and 11 - 12 years (Britton & Britton, 1969). However, these differences may reflect the different tasks required in the different studies which utilise a variety of materials ranging from black and white passport photographs to colour film segments.

Of the limited number of research studies for adults with learning disabilities, the most comprehensive and useful one is by Lipe-Goodson and Goebel (1983). This showed that those with learning disabilities may still be developing this skill as they age as adults. Key factors from the literature may include age, intelligence quotient (IQ), degree of institutionalisation and developmental level. However, the Lipe-Goodson and Goebel study (1983) also looked at the relationship between factors such as age, intellectual ability and the percentage of life spent in institutions, and found that some of these were inter-related. For instance, those with higher intellectual capacities (IQs) had more developed concepts of age and death than those with lower IQs, but that these differences reduced according to the percentage of time they had spent in institutional life. A recent study by Bell (1998b) shows that there may be thresholds at which it may be expected that the concept of age discrimination has developed. These thresholds are having an IQ level of around 60 - 65 using the Wechsler Adult Intelligence Scale - Revised (Wechsler, 1981) and having a developmental age equivalence of 8 to 9 years or

over as measured by the composite score in the Vineland Adaptive Behavior Scales (Sparrow et al., 1984). Additionally, this research showed that predictive signs of this ability were clients being able to state their own age *and* being able to place their own photograph correctly into an array of 6 age-bands over the life span. (Note: *both* of these signs together were required).

Although most of the research in this area dates from 15 to 30 years ago, there are some more recent discursive reports of education groups which aimed to teach age recognition skills. Briggs et al., (1996) described work with a group of sexual offenders who had learning disabilities and they found that dress cues were easier than facial cues or body posture. Other cues used by the adults included colour of hair, presence of wrinkles, the use of make-up, body size, style of clothes, height and pitch of voice (personal discussion by Hickey of Briggs et al., 1996). Another report of an education group for male sex offenders with mild learning disabilities, by Charman & Clare (1992), reported that the men in the group said that to determine age they could ask the person, and go by whether or not facial hair was present in men. However, they also used other cues which would not be as reliable such as height (in adults) and the presence of rings. These were practical, clinical groups and details of the evaluation of them was not given in the articles and the relationship with possible factors such as age and developmental level were not discussed.

Although, therefore, there is some evidence about factors which may be important, including current research emphasising certain thresholds of IQ and developmental stage (Bell, 1998b), there is no evidence of whether this ability may be increased with intensive teaching.

CASE HISTORY

Mr W. is a 43 year old man, living in a hostel for people with learning disabilities, with sleep-over staff. He was referred to the Department of Psychology following

several reports to the Procurator Fiscal that he had approached and talked to children in the street who were unknown to him. Upon investigation, the problem of speaking to children in the street was long-standing. Mr W. had lived in an institution for most of his life, went out to live in the community in 1988, but was returned almost immediately following complaints about his possible intent to molest children. He returned to the same community placement in 1994 and several more incidents of a similar nature followed.

Previous psychology reports suggested that he had not shown any obvious paedophile interest while he had been in the institution nor when assessed on previous occasions using the Socio-Sexual Knowledge and Attitudes Scale (Wish et al., 1980) There were several reports which advised reminders to him 'not to talk to youngsters' or people younger than himself outside the hostel, and which also reported his attendance at social skills groups. However, the fact that there were several referrals of this nature indicated that he would not or could not learn this skill. Many staff members feared he was a latent paedophile and others who did not, were concerned that he might appear so were he to face another criminal charge.

Clinical Psychological Formulation

The formulation was that Mr W. was a very friendly man, of possible mild learning disabilities, who was perhaps not able to discriminate age bands or to comprehend age terms, and that this was leading him to approach children inappropriately. He was consequently not being advised in a way which would assist him in keeping clear of the law and of allegations of paedophile intent to children.

Aims of Intervention

Assessment

1. To carry out a full assessment of intellectual ability and of developmental level in terms of social and adaptive behaviour, and to feed these back to care staff, and to compare these levels with the key levels found by Bell (1998b).

2. To carry out a current assessment of socio-sexual knowledge and attitudes to determine any paedophile interest.

3. To assess Mr W.'s understanding of language in order to target intervention at an appropriate level.

4. To assess assertiveness, suggestibility and compliance to assist in determining his ability to cope with police questioning and legal procedures, as well as discussions with carestaff.

Intervention

1. To investigate the effectiveness of an intensive teaching programme, to be carried out *in situ* on a one-to-one basis (with homework).

2. In the light of this, to provide evidence of change and/or advice as to future work and support for Mr W.

METHOD

Measures

A wide range of measures were utilised. These can be seen with the results in Table 1.

They include a measure of his intellectual level using the Wechsler Adult Intelligence Scale - Revised (WAIS-R) (Wechsler, 1981) and of his social and adaptive behaviour using the Vineland Adaptive Behavior Scales (VABS) (Sparrow et al., 1984). An assessment was made of his understanding of spoken language using the British Picture Vocabulary Scale (BPVS) (Dunn et al., 1982). The Socio-Sexual Knowledge and Attitudes Test (SSKAT) (Wish et al., 1980) was used as the basis of a structured interview to assess his knowledge in this area and any paedophile interest in children, and it was hoped to use the Gudjonsson Scales of Suggestibility (GSS) (Gudjonsson, 1984, 1987) to consider levels of suggestibility and compliance. Detailed reports of the contents of a previous social skills package devised by a clinical psychologist (SSP) were looked at and a set of follow-up sessions on the areas that had been covered were arranged to be carried out by an assistant psychologist.

The full range of measures used by Bell (1998b) were administered. Full details of the measures may be seen in Bell (1998b) but a resume of these measures follows: - A check is made to see if the person knows their own age.

- The Age Identification Test - Others (AIT-Others) uses a set of 6 photographs of males and 6 photographs of females. These are presented in pairs and the person is asked to say which of each pair is the 'oldest'. The sets of photographs contained one each of the following age bands : 0-4 years, 5-11 years, 12-15 years, 16-20 years, 21-59 years and 60- 90 years. The age bands had been chosen on the basis of previous research and used convenient educational and legal age limits. The pairs shown commence with all of the combinations which are 3 age bands apart, then 2 age bands apart, and then neighbouring age bands. A scoring system gives results in terms of percentage correct for each level and the mean of the three subscores is taken as the final score. The total possible score is therefore 100.

- The Age Identification Test - Self (AIT-Self) uses a photograph of the person taken on the same day using an 'instant' camera and it assesses whether or not the person can place this correctly into the array of photographs of the same sex, arrayed in ascending order of age. - The Index of Adulthood - Others (IA-Others) uses the same photographs as are used in the AIT-Others. All 12 photographs are shown in random order and the person is asked whether these are of an adult ('grown-up') or a child. The total possible score is 12.

- The Index of Adulthood - Self (IA-Self) is a measure which asks the person whether they are an adult ('grown-up') or a child.

The Cues measure is a more qualitative test in which the person is askeda) what cues they could use to determine age

b) what particular hobbies, interests and lifestyles they would ascribe to the people in the photographs, presented one at a time. If not commented on, they would be asked whether or not that person went to school.

A scoring system for parts a) and b) (Bell, 1998b) gives a possible score of 43. c) with the photographs from section b) (above) displayed one at a time, the person would be told the interviewer's age, reminded of their own age and asked to guess the ages of the persons in the photographs.

Procedure

Assessment:

All the measures were carried out before intensive training. The age recognition measures were repeated after the training period.

Intervention:

Sessions were held, at weekly intervals, each lasting about 1 and a half hours. The sessions and content are shown in Figure 1.

Insert Figure 1 here

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Within each *target age group session* (lessons 1 to 6), there was a period in the hostel of about half an hour discussing the specific age group, their possible likes, dislikes, hobbies and appearance, and a variety of photographs and newspaper and magazine clippings were used to comment upon. The second part of session was practical and involved walking with Mr W. around the local shopping area for about an hour to spot people from that age group and to discuss their appearance and likely interests etc.. There was also a 'homework' component in that hostel staff would concentrate their efforts in that week on the age group just covered.

Each *age discrimination session* (lessons 7 to 9) followed the same pattern as above but here the aim was to try to apply skills across the age ranges try to work out what age groups people would fall into, to use appropriate words to describe them (e.g. adult, 'grown-up', baby, child, old, young etc.) and to consider possible interests, hobbies and lifestyles e.g. 'she's maybe married', 'he's still at school', 'she plays with dolls', 'he maybe enjoys a game of golf', 'she's got a job' etc.

RESULTS

An overview of results of the measures is shown in Table 1.

Insert Table 1 here

Mr. W. had a Full Scale IQ of 56 which is lower than the level of 60-65 IQ which was suggested from the recent research (Bell, 1998b) to be important for the presentation of age recognition skills.

In terms of his social adaptive behaviour he was 'average' in relation to norms for people with learning disabilities living in the community. However, the age equivalence shown was below the threshold of 9 years age equivalence found by Bell (1998b) for the presentation of age recognition skills. When the Socialization
Domain was further divided into its Subdomains, it can be seen that the low level for Interpersonal Relationships, coupled with a low level of language comprehension (see BPVS results) and his poor memory skills (mentioned in the SSP report), were well hidden by a high level of Coping Skills. On appearance to an outsider, or officers of the law, Mr. W. would appear relatively more able than shown on testing.

No signs of a sexual interest in children were shown in the interview using the SSKAT.

His understanding of spoken single words (using the BPVS) was at an age equivalence of 6 years 9 months.

The scales of suggestibility and compliance (GSS) had to be abandoned due to his poor memory for the task and for the text used. However, clinical opinion was that he was very suggestible with a strong tendency to acquiesce and to be unable to state when he did not understand what was said to him. This was supported in the report made by the assistant psychologist on carrying out follow-up sessions on the SSP. She mentioned that he could be assertive if asked to do totally unreasonable things, but otherwise did not say if he did not understand what was asked of him, had problems remembering things, and tended to agree with the speaker. She added that his relatively good expression of language (but low comprehension of language) and his high level of coping skills would mislead people interacting with him.

On the age recognition measures, Mr. W. showed a fairly low ability. He did not know his own age either before or after the intensive training period and was unable to put his own photograph into the correct age band, choosing the 12-15 years age band on both occasions. However, he did appreciate that he was an adult. On looking at photographs, he was unable to use a number of years in guessing ages, and tended to give any number, or a number he had just heard. Also, when asked to discriminate the older of two people in the photographs (AIT-Others), he had a very low score which stayed almost the same even after intensive training. However, when asked to say whether photographs were of an adult or a child (IA-Others), he was almost completely correct at pre-intervention assessment and completely correct at post-intervention assessment. The post-intervention IA-Others measure was repeated in the same assessment session and once again, he scored full marks. There had been, therefore, a slight improvement noted. In relation to the cues used to determine age, he appeared to move slightly from only stating size as an indicator to mentioning other cues such as 'faces grow' and 'skin rough' but these were not sufficient evidence of using appropriate cues. When looking at the photographs, he appeared to comment only on size and the background features, with occasional comments on the likelihood of the person working and whether or not they went to school. Only the last two features would be reasonably reliable indicators to age bands. There was a very slight increase in scores for this measure from assessment at the pre-intervention stage to post-intervention but cues generally were extremely limited. Ad hoc questions within sessions revealed that *if asked* whether or not someone might have a job, he was reasonably accurate (about 75%), but he was almost completely accurate (nearly 100%) if asked whether or not the person went to school. For example, when a toddler was pointed out, he would reply that the person would not go to school, but if asked why not, he might reply 'because they're too old'. In other words, school/not school as a description was much more reliable than any expression of 'old' or 'young'. Care-staff were therefore advised accordingly to concentrate on school/not school as the most useful concept and to use this concept consistently across all staff members.

DISCUSSION

Whilst the research study by Bell (1998b) was ongoing, this intervention was attempted to try to educate Mr W. in age recognition skills. Unfortunately the intensive training programme did not show more than minor improvements on the new measures. However, in looking at the results from the study by Bell (1998b), it can be seen that Mr W. had a lower IQ than what appeared to be the threshold IQ band of 60-65. He also had a considerably lower developmental level than the 9 years age equivalence which had been shown as the threshold by which age recognition skills had usually developed. In the same study, joint predictors of having achieved this skill were *both* being able to state one's own age *and* being able to put one's own photograph into an array of age bands over the life span correctly. Mr W. was unable to do either task.

Mr W. was given 9 to 14 hours of intensive one-to-one teaching and this was supplemented by extra 'homework' with the hostel staff, yet this did not significantly affect his age recognition skills.

However, the intense intervention allowed the final report to be more detailed and gave more detailed instructions to hostel staff as to how to work with Mr W. For example, in the past he might have been asked not to talk to 'young' people, 'younger' people, 'people or children under 16', 'toddlers', 'young girls', to be warned that the person he had been seen talking to was 'only 12 years of age', or told only to talk to people 'of the same age'. These terms would all be meaningless. The final report to staff advised clear, consistent instructions using the concepts of 'grown-up'/child or at school/not at school for advice, warnings or education. Also, as a result of the information from the parts of the sessions conducted in the local area, the author was able to report that, *if reminded*, he did not stare at or talk to people inappropriately in the street.

In this case, therefore, the intensive treatment was a failure though it did provide a good basis for testing the findings of the study by Bell (1998b) and for the provision of a report which could more confidently assess Mr W's competence and could advise regarding his consistent management.

This case-study, therefore, helps confirm the findings of Bell (1998b), that there may be thresholds of intellectual level, of around IQ 65, and social adaptive behaviour, of around an age equivalence of 9 years, which are necessary before

age recognition skills are possible, and that the joint predictors suggested of having knowledge of one's own age *and* the ability to place one's own photograph into the correct age band, may be useful and reliable. The case-study, also, presents the failure of an intensive training programme to improve the age recognition skills of one person with learning disabilities. However, it does show the possible content and value of a detailed assessment of such an area and its relevance in providing management advice to care-staff. If this failure of intensive training is replicated in other research on those who show similar levels of intellectual and social adaptive behaviour, then it would support the concentration of training onto the group of people around and above the thresholds found in the study by Bell (1998b) in order to help them reach their potential in age recognition.

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TABLES AND FIGURES

MEASURE	RESULTS			
WAIS-R	Full Scale IQ of 56			
VABS	Age Equivalence for Domains :			
	Communication 5	years 0 months		
	Daily Living Skills 7	years 9 months		
	Socialization 5	years 11 months		
VABS	Comparison of Total Scores	with Norm Group of Learning		
	Disabled People Living in the Community :			
	Communication A	Average		
	Daily Living Skills	Average		
	Socialization A	Average		
VABS	Comparison of Socialization	Norm SubDomain Scores with Norm		
	Group of Disabled People Living in the Community : Interpersonal Relationships Below average			
	Play and Leisure Time	Average		
	Coping Skills	Above average		
SSKAT	No evidence of sexual interest in young children			
BPVS	Age equivalence of 6 years 9 months			
GSS	Unable to be carried out due to low level of ability. C opinion of high suggestibility and compliance.			
· ·				
SSP	Reported not to state if he did not understand somethin said to him and to have a tendency to acquiesce. Also difficulties reported in remembering things said to him			
	Good social skills and language use were noted.			
AGE MEASURES	PRE-INTERVENTION	POST-INTERVENTION		
Know own age?	Own age not known	Own age not known		
AIT-Others	21.66	20.83		
AIT-Self	Unable to select correct age	Unable to select correct age		
	band for own photograph.	band for own photograph.		
	Age band 12-15 years	Age band 12-15 years		
	chosen.	chosen.		
IA-Others	11	12. Repeated, score of 12.		
IA-Self	Identified self as 'grown-up'	' Identified self as 'grown-up'		
Cues a)	'when they're quite big'	'grow bigger', 'faces grow', 'skin rough'		
Cues b)	10	13		
	Comments on size, setting o	f Comments on school		
	photo, jobs, school	accurate, jobs fairly accurate		
Cues c)	Wild guesses at a number	Wild guesses at a number		
	e.g. 46 for a boy of 12-15	e.g. 86 for same boy on this occasion		

Table 1. Overview of measures and results (WAIS-R, VABS, BPVS, SSKAT, GSS, SSP and measures of Age Recognition).

Lesson	1 - Target age group -	0-4 years	
Lesson	2 - Target age group -	5-11 years	
Lesson	4 - Target age group -	16-20 years	
Lesson	5 - Target age group -	21-59 years	
Lesson	6 - Target age group -	60-90 years	
Lesson	7 - Age discrimination train	ning	
Lesson	Lesson 8 - Age discrimination training		
Lesson	9 - Age discrimination train	ning	

Figure 1. Overview of Age Recognition Training Plan

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Single Clinical Case Research Study II

SEX THERAPY IN A COUPLE WITH LEARNING DISABILITIES: A CASE STUDY

Prepared in accordance with guidelines for submission to 'British Journal of Learning Disabilities' (Appendix 7.1)

SEX THERAPY IN A COUPLE WITH LEARNING DISABILITIES: A CASE STUDY

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SEX THERAPY IN A COUPLE WITH LEARNING DISABILITIES : A CASE STUDY

SUMMARY

Despite greater emphasis in the last decade on sex education programmes for young people who have learning disabilities, there are few reports of the content and outcome of sexual or relationship counselling or of sex therapy for couples who have learning disabilities.

This case study discusses a couple who had been married for 7 months but who had been together for a year previously. Sexual intercourse had only been achieved, unsatisfactorily, on 2 occasions. There were no indications of any difficulties in either partner's sexual history (such as abuse), and their knowledge of sexual matters met the standard of routine education packages for people with learning disabilities.

A number of standard measures were amended and used to assess current functioning and to chart progress. For treatment, an approach in two phases was used.

Phase 1 provided in-depth educational material (using a book and video), and gave the opportunity for discussion and questions and encouraged better communication between the couple on sexual matters. At the end of this phase, the couple's frequency of sexual intercourse had increased to 2 times per week but this was still not satisfactory to the couple in either frequency or in quality. Phase 2 was therefore implemented, and used Masters and Johnson 'sensate focus' as treatment (Masters & Johnson, 1970). This raised the frequency of sexual intercourse to 4 times per week on average. The couple reported that they were delighted with the frequency and the quality of sexual intercourse and this was reflected in the scores on the amended measures.

BACKGROUND

In 1971, a United Nations Declaration asserted the rights of people with disabilities and this declaration became used in policies and statements of intent about working with this population. Since that time, there has been an increasing interest in providing high quality services in line with raising the standard to that which is valued by most of the population, and the tenets of 'normalisation' have become the basis of service provision for people with learning disabilities (Nirje, 1972; Wolfensberger, 1972, 1983). One area which has proved more difficult is the area of interpersonal relationships. In the 1980s there was concern that sex education was receiving little attention in schools for children with learning disabilities and this was addressed by education authorities and government bodies (Scottish Health Education Group, 1985). Thereafter, there was an increase in the number of sex education programmes (Craft et al., 1991), staff training initiatives (Brown, 1991; Brown & Craft, 1992; McCarthy & Thompson, 1993) and groups working on developing policies in this area (Brown, 1992). Although there has been considerable progress in this area, there is research which suggests that, frequently, those sexual relationships which develop, may not be enjoyed. McCarthy (1991, 1993) commented that women with learning disabilities generally do not enjoy heterosexual sexual intercourse and she reports that the reasons for this include ignorance of their own bodies and insensitivity or violence by their lovers.

There is also little research on the uptake of screening and the use of 'well-woman' clinics (reported in Brown, 1996) by women with learning disabilities. Also, once women with learning disabilities become parents, research shows that they tend not to receive the support they need (Booth & Booth, 1994) and that they receive special assistance only after reaching a stage of crisis (McGaw, 1996). There is also a dearth of literature on relationship or sexual counselling or on sex therapy for people with learning disabilities (See Frank, 1991, for one example).

Clearly, any couple looking for assistance with sexual problems, could present with inadequate vocabulary to discuss and understand the topics, and they may hold misinformation or have large gaps in their knowledge. Also, they may have had abusive and aversive past experiences, they may have been the victims of repressive institutions or staff groups, and they may find it difficult to understand the concepts being taught. Consequently, they may require a longer and more detailed teaching programme, to encourage the assimilation and retention of knowledge, and they may also require specialist therapy.

CASE HISTORY

Referral

Mr and Mrs M. were referred to the Department of Psychology by their GP as they had reported to her that they were unable to have sexual intercourse. Mr M. had said that he considered everything to be his fault and that his anxiety was the problem, and he had asked the GP for medication to reduce this. She had not considered this to be appropriate and had referred the couple instead for psychological help.

Mr M was 27 years old and Mrs M was 25 years old. They had been married for 7 months, and had been dating each other for the previous year.

Case Notes

Mrs M had been seen 2 years previously by the author, when she had been referred by her GP for relationship counselling. However, her relationship at that time, which had been non-sexual, foundered before she was seen, and because of this, treatment had covered sex education and issues of self-esteem.

First Appointment

Initial visits were arranged with the therapist assisted by a trainee clinical psychologist. The aim of the initial visits was to see if the couple had an otherwise satisfactory marital relationship and were motivated to work together with the support of the therapists. Had there been significant other difficulties in the relationship, these would have been addressed before or alongside the sexual difficulty. Other information was also gathered on their sexual histories (with each person seen separately by a therapist), on their knowledge of, and attitudes towards, sexuality, and on their comprehension and use of the language that would be required in treatment. Both partners had mild learning disabilities. Mr M. was working and Mrs M. attended a local Training Centre 2 days a week. They lived in their own house and received some support from members of their extended families but they required no support from authorities. The couple reported that they had had sexual intercourse only twice in the duration of their marriage (and none before this, by choice). They both wished to

have a fulfilling sexual relationship and also wanted to start a family.

Formulation and Research Question

Clinical assessment indicated that, although the couple had what would be seen as a reasonable knowledge of sex education for this population, this was of a rudimentary nature. It was thought that they had not learned enough to assist them in understanding their own and their partner's arousal patterns, nor enough about (normal) sexual practices. Also their own lack of experience and their lack of ability to read and apply details from books, magazines and films, severely limited their understanding and expression of sexuality.

The research question was whether informed discussion with supportive educational material at a level suitable to their degree of learning disabilities, would be sufficient to enable them to move to a more satisfactory sexual relationship, or whether a more psychoeducational approach, using Masters and Johnson 'sensate focus', would be required in addition (Masters & Johnson, 1970).

Assessment Measures

 Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)
 Sexual history by structured interview (based on the Sone Sexual History Background Form, Sone, 1984)

 Socio-Sexual Knowledge and Attitudes Test (SSKAT) (Wish et al., 1980)
 The Marital Adjustment Test (MAT) (Locke & Wallace, 1959), was amended for a learning disabled population and read out to the participants using adapted, simple language, and then marked by the therapist in collaboration with the clients (See Appendix 7.2 for the Adapted Marital Adjustment Test.)
 The Golombok-Rust Inventory of Sexual Satisfaction (GRISS) (Rust & Golombok, 1986) was amended for the learning disabled population and read out to the participants using adapted, simple language, and then marked by the therapist in collaboration with the clients (See Appendix 7.3 for the Adapted Golombok-Rust Inventory of Sexual Satisfaction).

6. Notes were kept at each stage of the frequency of intercourse.

METHOD

Fortnightly sessions were agreed, each of one hour's duration. For most of these both therapists were present, enabling assessments to be carried out separately, and allowing issues to be raised separately if required, although such issues were all discussed together later. The initial plan was to carry out a full assessment and then to carry out treatment through detailed education at a level suited to their difficulties. From the beginning however, it was considered that a more specific psychoeducational approach may well be required. This did indeed prove to be the case. Treatment, therefore, was in two phases.

Phase 1

During this phase of 5 sessions, the material used included the book, 'The Joy of Sex' by Alex Comfort (1996 edition). Although neither partner could read, this edition features a great many drawings of sexual activities and of sexual positions. The video, 'The Essential Lovers' Guide' (Stanway, 1996), was also given to the couple for viewing at home.

Phase 2

This phase also lasted for 5 sessions. It used the 'sensate focus' approach of Masters and Johnson (1970) in which there is a ban on sexual intercourse, with the couple proceeding through a series of stages ending with the reintroduction of sexual intercourse. The first stage of non-genital sensate focus involved the couple touching and caressing each other in turn on any part of the body other than the genital areas or the woman's breasts. The aim was to explore, to give and receive pleasure and to build up communication about what each other liked and disliked. The second stage of genital sensate focus meant that the couple learned to enjoy and touch each other's genitals and the woman's breasts using different kinds of touch and again to build up communication. Gradually intercourse was reintroduced, starting with the woman-above position and, initially, without movement.

RESULTS

1 Results of measures carried out at Baseline

SEXUAL HISTORY

No significant events, such as abuse, were reported that required specific input. Neither partner had had previous experience of sexual intercourse with other partners. Both received considerable teasing from their extended families about their sexual relationship, which hinted at sexual inadequacies, and not surprisingly, the couple were unable to talk to their respective families about difficulties. Neither has close friends of the same sex.

SSKAT.

This was used with both partners. No significant gaps in knowledge were uncovered and the language used contained either the correct medical terms or common colloquial expressions. Both partners had reservations about masturbation, considering it to be morally wrong, but they did not feel this about sexual intercourse itself or about foreplay.

HADS

Mrs. M's scores on the HADS showed moderate anxiety which appeared from clinical interview to be due to pressures on her from the extended family about their sexual activities. Despite Mr. M's request to his GP for help with anxiety, the anxiety component of his HADS score was low (See Table 1).

MAT

The scores of 148 (Mr M.) and 146 (Mrs M.) reflected good marital adjustment (See Table 1). In the Locke and Wallace sample (1959), the mean of the well-adjusted group was 135.9 and the maladjusted group was 71.7. Only 7% of the maladjusted-adjusted group achieved scores of 100 or more, whereas 96% of the well-adjusted group achieved scores of 100 or more.

GRISS

The transformed subscores of the GRISS were plotted as in Figure 1. This showed specific areas of possible difficulties. A score of 5 or more is reported to indicate a problem (Golombok & Rust, 1985). The Handbook of the GRISS (Rust & Golombok, 1986, p.21) states that 'a set of scores of 1 straight across the board

would be exceptional. As yet no profiles with no scores above 3 have been found, and even those would only be expected during the heyday of a good relationship'. At Baseline the following areas in the profile showed transformed subscores which were ≥ 5 (which may have indicated a problem) :- impotence, premature ejaculation, male avoidance, infrequency, female avoidance, female non-sensuality and vaginismus.

FREQUENCY OF LOVEMAKING

The frequency of love-making was 0 times per week.

Insert Table 1 and Figure 1 here

2 Results of Measures used at the end of Phase 1

HADS

Mrs. M's score on the HADS still reflected moderate anxiety (See Table 1). She still spoke of family pressures on her. She had become pregnant by this stage and fears about the pregnancy and birth also preoccupied her.

MAT

At this stage, Mr. M's score had changed very slightly from 148 to 141, still higher than the mean of the well-adjusted group in the Locke and Wallace (1959) study. Mrs. M's score had gone down from 146 to 123 (See Table 1). The mean of the well-adjusted group in the Locke and Wallace study (1959) was 135.9 and the mean of the maladjusted group was 71.7. The therapists considered that the lowered score reflected Mrs. M's dissatisfaction with what she perhaps considered was not enough progress in improving the sexual side of her marriage.

GRISS

The transformed subscores of the GRISS were plotted as in Figure 1. At the end of Phase 1, the following areas in the profile showed transformed subscores which were ≥ 5 (which may have indicated a problem) :- impotence, male dissatisfaction, infrequency, female non-sensuality and vaginismus. The rise in subscore for anorgasmia from Baseline to the end of Phase 1 can be explained from the fact that ability to reach orgasm at Baseline was based on a high success rate from only 2 episodes of intercourse, whereas at the end of Phase 1 there was a lower success rate based on a higher frequency of intercourse.

FREQUENCY OF LOVEMAKING

Frequency had increased to 2 times weekly on average. Both partners considered that this was not sufficient for them, although they were pleased at progress. Clinical interview showed that they spent very little time on arousal and sexual contact.

Reconsideration of Treatment

At this stage, despite having been requested to use a reliable contraceptive method during treatment, Mrs M became pregnant. An informed prediction had to be made whether the progress made might continue gradually, or whether the pregnancy and its anxieties, might make this difficult. Despite therapists' concerns that the couple might not wish to accept a ban on intercourse whilst 'sensate focus' treatment progressed, both partners understood the rationale of treatment and agreed to follow the recommendations of the therapists. They appeared to accept that a gradual approach to intimacy was being recommended and that the full reintroduction of sexual intercourse was planned within the near future.

3 Results of measures at the end of Phase 2

HADS

At this stage, neither Mr. M nor Mrs. M. had scores on the HADS which reflected even moderate levels of anxiety or depression (See Table 1).

MAT

Both scores of 158 (Mr. M) and 141 (Mrs. M) reflected good marital adjustment (See Table 1).

GRISS

The transformed subscores of the GRISS were plotted as in Figure 1. At the end of Phase 2, *no* subscore was above 2, perhaps showing sexual satisfaction at the level expected in the 'heyday of a good relationship' (Rust & Golombok, 1985, p.21).

FREQUENCY OF LOVEMAKING

This had increased to 4 times weekly and the couple reported that this lovemaking was enjoyable and that they now took considerable time over it. Both indicated that they were delighted with the outcome of treatment and that they did not require further assistance.

DISCUSSION

It had been considered that the opportunity for straightforward, private discussion, suited to the level of comprehension of language and the degrees of learning disabilities, accompanied by clear educational material, might be sufficient to teach normal sexual practices, to encourage communication and to assist the couple to enjoy their own sexuality. Standardised assessments used in sex therapy for people within the normal population were amended to suit a couple with learning disabilities. The couple's personal reports and these formal measures indicated that, despite an increase in the frequency of lovemaking, there were still problems. A 'sensate focus' approach (Masters & Johnson, 1970) was then used, with great success, and this progress was also noted in the formal measures. This two stage approach is recommended for use with other similar couples as it allows time for the couple to absorb information at their own pace and level without the intervention being seen as a 'treatment' for a clinical 'problem'. It also means that the transition to a more formal treatment phase, if this is required, is more easily accomplished, as a common knowledge and language has been established and any embarrassment has already decreased. On a practical level, any staff using this approach have to be able to cope with extremely to-the-point questions and answers, and they have to be practical and creative in using and adapting many different types of material to educate and explain. It is important to note that, although both partners had received sex education whilst in school, and the young woman had received one-to-one sex education from the author two years previously, they had not been able to achieve sexual satisfaction as a couple in their marriage. This may have implications for other heterosexual and homosexual relationships. Satisfaction in sexual relationships may be related to the adequacy of sex education in growing up and the availability

later of sexual counselling and sex therapy. The recent work of McCarthy (1991, 1993) reported the general lack of enjoyment of sexual intercourse of women with learning disabilities and reported also that this is due to ignorance about their own bodies and due to insensitivity by their partners. Consequently, perhaps a more proactive approach needs to be considered in the whole field of human relationships for those who have learning disabilities.

ACKNOWLEDGEMENTS

I am grateful for the participation of the couple in this study and for the assistance of Ms Laura Toplis, Trainee Clinical Psychologist.

TABLES AND FIGURES

	BASE	LINE	END ()F PHASE 1	END C	OF PHASE 2
	MrM	MrsM	MrM	MrsM	MrM	MrsM
мат						
	148	146	141	123	158	141
HADS						
Depression	0	4	0	3	1	0
Anxiety	4	8	1	8	• 1	2

 Table 1. Results of MAT and HADS for Mr. M. and Mrs. M. at Baseline, end

 of Phase 1 and end of Phase 2.



Figure 1. GRISS profiles at Baseline, end of Phase 1 Treatment and end of Phase 2 Treatment

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Small Scale Service Evaluation Project APPENDIX 1.1

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British Journal of Learning Disabilities

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Articles should be typed, double-spaced, on one side only of A4 paper, with a 1.5" margin o each side. Pages should be numbered consecutively in the top right-hand corner, commencin with the title page.

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The text should be written in the third person, in 'plain English', with an international, mult disciplinary readership in mind. Descriptions should be clear and concise and terminology specific to a particular profession should be explained for the benefit of people in other professions

Care should be taken to use non-sexist language and, when referring to disabilities etc., t emphasise the person rather than the disability, so descriptions such as *people with learnin* disabilities should be used rather than the learning disabled. Clumsy expressions such as he/sh he or she or s/he should be avoided, for example, by using the plural verb. Use the ter 'participants' to describe those involved in research rather than 'subjects'. Full references to the sources of all statistical measures used must be supplied.

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COPIES

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Each Table and Figure should be presented on a separate sheet at the end of the work. Each one should be numbered in Arabic numerals and given an appropriate heading. The preferred position in the text should be indicated in the left-hand margin and the text should refer to each Table or Figure in turn.

165

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Glossy, sharply defined, black and white photographs are preferred. Each one should be lightly numbered in pencil on the reverse. A list of the photograph numbers and their respective relevant captions should be typed on a separate sheet. The author(s) must seek all relevant rights and permissions for using the photographs and must enclose a letter stating that these have been obtained.

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Book chapters	Oliver, C. (1993) Self-injurious behaviour: from response to strategy. In C. Kiernan. (ed) <u>Research to Practice? Implications of Research on the Challenging</u> <u>Behaviour of People with Learning Disability</u> . Clevedon: BILD Publications

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Letters which either provide or seek information on any aspect of research into learnin disability and its associated conditions are welcome, as well as those which discuss the conter of previous *British Journal of Learning Disabilities* articles. The first name, surnam professional occupation, and address of the correspondent(s) should be given at the end of th letter. Any references quoted should be listed on a separate sheet and prepared in accordance with the guidance given above for *Article References*

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Small Scale Service Evaluation Project

APPENDIX 1.2

The Staff Support Questionnaire : Results

1 - Role Ambiguity/ Clarity

1) How clear are you about the main	Very clear/ clear	76.5%
objectives you should be working towards	Unclear/ very unclear	11.7%
in your job?	Undecided	11.7%
2) How clear are you about what your	Very clear/ clear	64.7%
superior expects from you?	Unclear/ very unclear	17.6%
	Undecided	17.6%
3) How clear are you about the limits of your	Very clear/ clear	82.4%
authority and responsibility in your present	Unclear/ very unclear	11.8%
position?	Undecided	5.9%
4) How clear are you about how satisfied	Very clear/ clear	35.3%
your work superior is with what you do?	Unclear/ very unclear	41.2%
	Undecided	23.5%
2 - Practical Support in Crisis Situations		

1a) Is there somebody you can talk to at work if	Yes	70.6% you
are experiencing difficulty in your job?	No	29.5%
b) How satisfied are you with this?	Very satisfied/	58.9%
	satisfied	
	Dissatisfied/	29.4%

very dissatisfied

Undecided 11.8%

Small Scale Service Evaluation Project

APPENDIX 1.2 continued

2a) If you were unable to cope with a situation at	Yes	100%
work, is there anyone you can call on for practical		
help?		
b) Is there always someone available?	Yes	76.5%
	No	23.5%
c) How long does it usually take for help to	> 5 mins	12.5%
arrive (in minutes)?	< 5 mins	87.5%
	> 10 mins	0 %
d) How satisfied are you with this?	Very satisfie	d/ 82.4%
	satisfied	
	Dissatisfied/	0%
	very dissatisfied	
	Undecided	17.7%
3a) Do you receive regular supervision sessions	Yes	23.5%
or performance reviews as part of a structured	No	76.5%
programme of staff development?		
b) How satisfied are you with this?	Very satisfie	d/11.8%
	satisfied	
	Dissatisfied/	47.1%
	very dissatisfied	
	Undecided	41.2%
3 - Identification of Risk Situations		

	Don't know	11.8%
at your place of work?	No	23.5%
1a) Have risk situations been clearly identified	Yes	64.8%
Small Scale Service Evaluation Project

APPENDIX 1.2 continued

b) If yes, were you involved in identifying	Yes	81.9%
the risks?	No	22.2%
2a) Have clear guidelines been established about	Yes	52.9%
what to do if something goes wrong?	No	35.3%
	Don't know	11.8%
b) If yes, do you agree with the guidelines?	Yes	77.8%
	No	22.2%
4 - Overall Job Satisfaction		
1a) I am satisfied with my present situation at work	k. Agree	41.2%
	Disagree	35.3%
	Undecided	23.5%
b) I am satisfied with my present level of involvem	ent	
in decision making at work.	Agree	52.9%
	Disagree	23.5%
	Undecided	23.5%
c) I am satisfied with the degree of support I	Agree	29.4%
receive in my job.	Disagree	41.2%
	Undecided	29.4%
d) I often think about finding another job.	Agree	52.9%
	Disagree	41.2%
	Undecided	5.9%

Small Scale Service Evaluation Project APPENDIX 1.3

Organisational support	Available or not	Staff responses
1)A clear written statement of service aims,	YES	YES = 9
published or endorsed by senior management,		NO = 4
given to staff to read.		D/K= 3
		(No reply $= 1$)
2)Written individual service plans for each res	ident YES	YES = 13
containing specific objectives covering a broad	d	NO = 1
range of needs.		D/K = 2
	(N	to reply $= 1$)
3)Weekly staff meetings whose prime function	n NO*	YES = 0
is to monitor the progress of individual resider	nts.	NO = 15
*Note: monitoring of the progress of residents		D/K = 1
took place by a different format.	1)	No reply $= 1$)
4)A nominated Key Worker for each resident	YES	YES = 14
whose role it is to co-ordinate specific actions		NO = 1
identified in the individual's service plan.		D/K = 1
	1)	No reply $= 1$)
5)A staff appraisal system in regular use.	YES	YES = 7
		NO = 8
		D/K = 1

(No reply = 1)

Table 4. Awareness of Organisational Supports using the OrganisationalVariables (Hewson and Walker, 1992)

Small Scale Service Evaluation Project APPENDIX 1.4

ATTITUDES TO PEOPLE WITH CHALLENGING BEHAVIOUR (APCB)

Challenging behaviour here refers to:

- aggression to people, to staff/residents/visitors/outsiders, and it includes threats of violence
- incidents of self-injury
- destructive behaviour, damage to property/belongings etc.

Would you please rate **your** emotional reactions to episodes of challenging behaviour on the following scales:

Please consider the episodes of challenging behaviour in the last month that you were involved in. What is your general view of the likelihood of making change **eventually** in the clients who show aggressive behaviour (including threatening behaviour)?

rarely possible

Small Scale Service Evaluation Project APPENDIX 1.4 continued

For recent episodes of challenging behaviour, what were your usual emotion reactions on the following scales?:	onal
• sadness/concern for the person showing the challenging behaviour	
no sadness	very sad
• frustration/upset	
no frustration	very frustrated
• annoyed at the client	
no annoyance	- very annoyed
• confidence at managing the episode	
no confidence	 very confident
• empathy/sympathy with the person showing the challenging behaviour	
no empathy/ no sympathy	very empathetic/ very sympathetic
• despair/helplessness	
no despair	 very despairing
• excitement at coping with such problems	
no excitement	_ very excited
• anger at client	
no anger	- very angry

Small Scale Service Evaluation Project APPENDIX 1.4 continued

•	fear	
no	fear	very frightened
•	satisfaction at managing to deal with it effectively	
ver	y unsatisfied ————————————————————————————————————	- very satisfied
•	feeling a need to help the person showing the challenging behaviour	
no of to	feeling a need help	very much – feeling a need to help
•	disgust/aversion to the client	
no of	feelings disgust	_strong feelings of disgust

THANK YOU FOR YOUR HELP IN COMPLETING THIS QUESTIONNAIRE

Small Scale Service Evaluation Project

APPENDIX 1.5

INDEX OF PSYCHOLOGICAL WELL-BEING (Berkman, 1971)

Here is a list that describes some of the ways people feel at different times. Please indicate how often each of these happen to you by putting a tick in the appropriate box.

Items	Never	Sometimes	Often	Score & Weight 0, 1, 3
Very lonely.				
Pleased about having accomplished something.				
Depressed or very unhappy.				
So restless you couldn't sit long in a chair.				
Particularly excited or interested in something.				
On top of the world.				
Vaguely uneasy about something without knowing why.				
Bored.				

Total

APPENDIX 2.1

Journal of Intellectual Disability Research

Information for contributors

Papers (in English) should be sent to the Editor, *Journal of Intellectual Disability Research*, University of Wales College of Medicine, Meridian Court, North Road, Cardiff CF4 3BL, Wales, UK. Papers are accepted on the understanding that they have not been and will not be published elsewhere. The original and two copies should be submitted to aid refereeing and these should be typed (with a wide margin), double spaced, on one side of standard paper $(A4-30 \times 21 \text{ cm})$. A title page should contain the author's name(s), place of work, address for correspondence, full title and short running title. Authors should retain one copy of the text, tables and illustrations as the editor cannot accept responsibility for damage or loss of manuscripts.

Page proofs must be returned to the Publisher within three days of receipt. Typographical errors and essential changes can be made at this stage. Major text alterations cannot be accepted. One free copy of the relevant issue will be distributed by the corresponding author to each co-author. Offprints may be purchased at prices determined by the Publisher by returning the form enclosed with page proofs.

The author should provide up to six keywords to aid indexing. Please note that 'intellectual disability', as used in JIDR, includes those conditions labelled mental deficiency, mental handicap, learning disability and mental retardation in some locales or disciplines.

Full reports of 1500–3000 words are suitable for major studies, integrative reviews and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions. Brief reports of 500–1500 words are encouraged, especially for replication studies, methodological research and technical contributions.

The text should proceed through sections of Abstract, Introduction, Materials and Methods, Results and Discussion. Tables and figures should be submitted on separate sheets and referred to in the text together with an indication of their approximate position recorded in the text margin. The reference list should be in alphabetical order thus:

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Moss T.J. & Austin G.E. (1980) Pre-atherosclerotic lesions in Down's syndrome. Journal of Mental Deficiency Research 24, 137-41.

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Spelling should conform to *The Concise Oxford Dictionary* of *Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units. Illustrations should be labelled with the figure number and author's name in soft pencil on the back identifying the top edge. Photographs should be glossy bromide prints of good contrast and well matched, preferably with a transparent overlay for protection. Colour photographs will be allowed only in special circumstances and the author will be asked to contribute towards the cost of reproduction. Line diagrams should be drawn with black ink on tracing paper or white card, or supplied as glossy prints. Papers may be judged to require extra-rapid publication by the Editor and referees.

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ETHICS OF RESEARCH COMMITTEE

APPLICATION FORM FOR ETHICAL APPROVAL OF RESEARCH PROTOCOL

1. TITLE OF PROJECT

AGE RECOGNITION IN ADULTS WITH INTELLECTUAL DISABILITIES

2. NAME AND ADDRESS OF PRINCIPAL APPLICANT FOR CORRESPONDENCE

Dorothy M. Murray (nee Bell) Head of Specialty, Learning Disabilities Psychology, Clinical Services Centre R.S.N.H. Larbert Stirlingshire FK5 4SD

- 3. NAME, DESIGNATION AND AFFILIATION OF ALL APPLICANTS (Research supervisor. if not applicant. should also be given).
- Dorothy M. Murray, Consultant Clinical Psychologist and Head of Specialty of Learning Disabilities Psychology, Community and Child Health Directorate of Central Scotland Healthcare NHS Trust. Qualifications : M.A., B.A. (Hons..), M. App.Sci.., C. Psycho.
- Research Supervisor : Professor Colin A. Espie, Department of Psychological Medicine, University of Glasgow, Academic Centre. Gartnavel Hospital, 1055 Great Western Road, Glasgow.
- 4. SIGNATURE OF APPLICANT(S) AND DATE OF SUBMISSION



5. SUMMARISE APPLICANTS' EXPERIENCE DIRECTLY RELEVANT TO THE PROPOSED RESEARCH TOPIC, SUBJECTS AND METHODS

The applicant has 12 years' experience as a clinical psychologist, mostly working in the field of learning disabilities. The clinical training for the Master's degree in Clinical Psychology (M. App. Sci.) included research training. A research study was carried out concerning social and marital adjustment of patients who had a temporary or permanent colostomy.

The Doctorate course for which I have received a place with my research proposal, extends this research training. My supervisor, Professor Colin Espie, is also very experienced in the field of research with adults with learning disabilities and he is a well respected clinician.

6. LIST ALL THERAPEUTIC RESEARCH *INVOLVING THE TREATMENT OF PATIENTS* IN WHICH APPLICANTS WILL BE INVOLVED CONCURRENTLY WITH THE PROPOSED RESEARCH.

There will be no psychological research carried out concurrently with the proposed research.

7. WHAT IS THE PRIMARY PURPOSE OF THE PROPOSED STUDY? (Tick ONE only)

Original biomedical investigation for peer-reviewed publication......

Original epidemiological / social scientific investigation for peer reviewed publication.....

Trial required by statutory bodies for product licensing purposes......

Post-marketing surveillance.....

Service evaluation audit.....

Undertaken as part of an educational qualification.....

Other (please specify).*.. As part of the Doctorate in Clinical Psychology (D. Clin. Psy.) which is part-time, over a period of two years.

8. AIMS AND OBJECTIVES OF THE STUDY

The ability of children to classify accurately the ages of self and others has been the subject of some research. Their ability appears to improve with age and their experience of others. However, perception of one's own age may well be related to how one feels, one's social situation, experience and physiological condition. Common difficulties of age-inappropriate behaviour shown by learning disabled adults may be related to problems in age identification of self and others, and IQ, age, and years of institutionalisation, as well as limited socially adaptive behaviour, may well be important factors.

The proposed study will attempt to examine age recognition of self and others in a group of 20 learning disabled adults from within a major institution and the wider community.

9. SCIENTIFIC JUSTIFICATION FOR THE STUDY (WHY IS THIS STUDY WORTH DOING? WHAT *NEW* INFORMATION WILL IT PROVIDE?

Knowledge of age, both of others and of self, is important in society for the development of appropriate social behaviour, and breaches of what is deemed to be socially appropriate behaviour may lead to very negative views of the person by other members of society, even where no criminal act is considered or carried out. For example, society has very firm views about the parameters of `rough and tumble' play between an adult and a child, and behaviour around and away from the margins of normally acceptable behaviour in this area may be seen in a very negative light.

There has been little research around the abilities of adults with learning disabilities to recognise age or label age, but there are studies of age identification within the normal child population which yield some ideas as to how these concepts may develop. Both the child's own age and his/her experiences of other people of different ages have been found to be related to the ability to judge the ages of others. Research by Sheehan (1978), Shelton (1961), Rudy and Goodman (1971) and Kratochwill (1973) suggest that it is part of a developmental process in intellectually average children related to age and experience.

For *own* age perception, the process appears different and research by Lipe-Goodson and Goebel (1983) suggest relationships with intellectual level and the number of years of institutional life for adults with learning disabilities.

A failure to identify age accurately may result in inappropriate social behaviour such as play with young children, and perhaps the assumption of a deviant interest in young children by care staff or parents, or actual but mistaken deviant activity with young children. It is hoped that the research will throw further light on several important issues :

- whether abilities in age identification of others and age perception of self are related to chronological age, IQ, social maturity and experience of institutional life - whether a simpler choice of adult/child aids the success of this task

It is also hoped that the research will pave the way for teaching in this area and in developing standardised measures of age recognition.

10. STUDY DESIGN AND METHODS

Subjects :

A range of subjects of different ages, intellectual levels and experience of institutions will be sought. Twenty volunteer adults who may or do receive learning disabilities services from Central Scotland Healthcare NHS Trust will be recruited. The subject group will include clients living in the community as well as those placed in R.S.N.H. Subjects will be between 18 and 75 years of age. Tests and Measures :

•

a) Age perception and identification tests. These are being developed using

photographs. The tests will ask for a comparison of photographs from different age bands and for a simple adult/child choice.

b) Intellectual test. The Wechsler Adult Intelligence Scale - Revised (WAIS- R) will be used.

c) Socially adaptive behaviour. The Vineland Adaptive Behavior Scales (VABS) will be used.

Settings and Equipment :

Testing will take place in a number of settings e.g. 'quiet' rooms on wards in R.S.N.H., private rooms in health centres, psychology offices etc.

Data Analysis :

A full statistical analysis of the results will be carried out and supervised as part of the Doctorate in Clinical Psychology.

Time Scale for Data Collection : October 1996 to April1997. Thesis presentation by August 1, 1998

11. WHAT ARE THE CRITERIA FOR SUBJECT INCLUSION / EXCLUSION?

Inclusion criteria :

Subjects will be within the remit of the learning disabilities service. This may include clients who show 'borderline' intellectual levels upon actual testing but they will be included if they have been deemed to be suitable to receive the services of the professional staff in that service.

Exclusion criteria :

Excluded will be those unable to be tested using the WAIS-R for reasons due to extremely low IQ level, a physical or neurological disability that would preclude this measure of testing IQ, extreme severity of challenging behaviour that would preclude the investigation for reasons of safety, those with a dementing illness, and those too acutely ill or medicated to participate.

12. TO WHAT RISKS WILL SUBJECTS BE EXPOSED? (Include

discomfort, distress and inconvenience)

None. Indeed, the subjects find the administration of the WAIS-R to be fun and the age recognition tasks should also be enjoyed as a 'game'.

There will be no inconvenience as care will be taken to carry out the practical aspects to suit the patients' normal daily timetables.

13. SUBSTANCES TO BE GIVEN TO SUBJECTS AS ADDITIONS / ALTERNATIVES TO NORMAL CLINICAL MANAGEMENT (For each substance give NAME, STATUS*, ADMINISTRATION (method, amount, frequency), POTENTIAL HAZARDS / RISKS, POTENTIAL BENEFITS)

* CTMI	P Clinical trial on	DDX	Doctors or dentists
	marketed product	e	xemption
CTC	Clinical trial certificate	Unlicensed	Unlicensed product or use
CTX	Clinical trial exemption		

N/A

14. ARRANGEMENTS FOR SUPPLY AND CONTROL OF DRUG STOCKS

N/A

15. ACTIVITIES EXTRA TO NORMAL CLINIC MANAGEMENT :

- a) Blood samples (number / amount) N/A
- b) Radiation exposure (type / site / number) N/A
- c) Biopsies (site / method / size / number) N/A
- d) Anaesthesia N/A
- e) Additional visits to hospital / Clinic / Practice (number) N/A
- f) Other procedures (specify nature and number; include psychological interventions, interviews / questionnaires)

No measures other than those already discussed :

WAIS-R and VABS are standard tests used in learning disabilities giving useful information for staff and help in the appropriate future placement of clients.

Age Recognition Tests have often been tried ad hoc but up to now there has been no attempt at developing standardised tests.

16. HOW LONG WILL INDIVIDUAL SUBJECTS BE INVOLVED IN THE STUDY?

Individually 1 - 2 hours, but the time will be spread out to suit the subject.

17. WHAT MEASURES WILL BE TAKEN TO IDENTIFY AND EXCLUDE SUBJECTS RECENTLY OR CURRENTLY INVOLVED IN OTHER RESEARCH PROJECTS?

Currently, I will not involve clients already involved in other psychological research. Medical personnel will also be written to for approval so that if necessary the subject can be withheld from the study by the medical practitioner.

18. HOW IS THE SUBJECTS' INFORMED CONSENT TO BE

ENSURED? (Enclose copies of all Patient Information Sheets and Consent Forms.)

Enclosed :

Patient Information Sheets - The client will have the information read out and explained at their own level of language comprehension. There will be opportunities for questions and further explanations. (See Appendix 3.2) Consent Forms - The client will sign or make their mark on the Consent Forms. (See Appendix 3.3)

Staff will also sign to show that they were present during the explanation and consent-signing and that they are satisfied consent has been given with understanding of the issues. If the staff member is not at the level of Care Manager or Care Leader (or equivalent), the Care Manager, or Care Leader will also state that they are satisfied at the staff member's decision and of the client's ability to understand the issues and to consent.

19. HOW WILL THE CONSENT OF THOSE INVOLVED IN THE CLINICAL CARE OF SUBJECTS, INCLUDING SUBJECTS' GPs, BE OBTAINED? (Where case records are to be accessed, the permission of the relevant Consultant and Medical Director is required.)

For all subjects, the relevant G.P. or medical professional will be written to with details of the research study and its value to the body of knowledge as well as potential benefits to the understanding of the difficulties of their specific patient. The full research proposal may be viewed by any of medical personnel involved upon request. If they do not wish their patient to take part, then this will be respected.

20. HOW WILL THE CONFIDENTIALITY OF RESEARCH RECORDS BE ENSURED?

Data collection materials will not contain the client's name but will only have a number attached. The key will be held by the main applicant. No-one else other than the main applicant will have access to the names. The final report in the medical file is subject to the normal contidentiality rules.

21. WHAT IS THE SOURCE OF FUNDING FOR THIS STUDY?

There is a request currently to the Research and Development Fund of Central Scotland Healthcare NHS Trust for funding of the fees for the two-year Continuing Professional Development Doctorate (part-time).

22. FINANCIAL INTEREST OF APPLICANTS IN STUDY

a) Will the study result in a financial payment (or payment in kind) being made :

to the applicants personally	
To a department (or similar) research fund	
Other (please specify below)	
No financial interest* no financial interest	

b) IF PAYMENT IS BEING MADE TO APPLICANTS PERSONALLY. SHOW THE MAXIMUM POSSIBLE TOTAL PAYMENT AND HOURS WORKED FOR ALL APPLICANTS COMBINED, ASSUMING MAXIMUM RECRUITMENT OF SUBJECTS

Maximum possible

Total	payment (£)
Total	hours worked

23. WHAT ADDITIONAL COSTS WILL BE INCURRED BY THE NHS THROUGH THE CONDUCT OF THE RESEARCH ; AND HOW WILL THEY BE MET?

None

24. WHAT ARRANGEMENTS ARE THERE FOR COMPENSATION IN THE EVENT OF INJURY?

Not applicable. ABPI guidelines...... Other (specify)......

25. WILL THE APPLICANT(S) AND FORTH VALLEY HEALTH BOARD BE INDEMNIFIED BY THE DRUG MANUFACTURER?

26. PLEASE INDICATE ANY FURTHER ETHICAL CONSIDERATIONS AND HOW THEY WILL BE ADDRESSED.

None

27. SUPPORTING PAPERS. PLEASE TICK / LIST ALL ENCLOSED.

Patient Information Sneet
Written Consent Forms
Interview schedules/questionnaires
Written statement of acceptance of ABPI guidelines
Others (list) :

Letter from Glasgow University showing acceptance of my research proposal for the Doctorate in Clinical Psychology with the signature of my Supervisor, Professor Colin A. Espie.

Major Research Project Proposal Appendix 3.1 continued

Direct Line: 0141 211 3903

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UNIVERSITY of GLASGOW

CAElew

23 August 1996

Dorothy M Murray Psychology Department RSNH Old Denny Road Larbert FK 5 4SD

Dear Dorothy

Re. D. Clin. Psy. by Part-time study.

I am pleased to advise you that your research proposal has been accepted as a suitable topic for research study over the two year period commencing October 1996. I should be grateful if you would complete the attached form as soon as possible, and return the original to Alison Spurway, Clerk to the Faculty of Medicine at the University of Glasgow and send a copy of it to Kate Davidson. The University will contact you thereafter concerning matriculation and your payment of fees.

Your research supervisor will be Colin Espie and you should contact him during October for an intitial discussion. The first block of teaching will be during the week beginning Monday 18th November and Kate will provide you with a full timetable for that whole week in due course. Please keep this free in your diary. You will be asked to give a brief presentation on your research proposal on 18th November.

Many congratulations, and we hope you are looking forward to what is going to be two years hard (but rewarding) work!

Please confirm your acceptance of this place by return.

Yours sincerely,

Professor Coun E Espie

Dr Kate Davidson

enc

DEPARTMENT OF PSYCHOLOGICAL MEDIC**NUZ** Academic Sentre, Gartnavel Roval Hospital, 1055 Great Western Road, Glasgow G12 JNH Professor Sir Michael Bond – *Head MiCreogramment*, Dr.R. V. Hertington Traephone: 01+1-211 J601 Stat (1-1-1-100

Major Research Project Paper

APPENDIX 3.2

SUBJECT INFORMATION LEAFLET

(This leaflet will be read to the subject and words used to explain the content will be suited to their level of comprehension of language.)

This research is to see how good people are at saying what someone's age is. A lot of other people will be asked the same things. There are a few things to do.

1) There is an intellectual test. This is a way to tell how your mind works, what it is good at and what it finds hard. Most people enjoy doing this test because it is like a lot of short games.

2) There will also be a way to see how good you are at what is called socially adaptive behaviour. That means that the staff (or your parents(s) if you live at their home) will be asked about things you can do or understand.

(Examples may be given to explain the above, according to the subject's expected level of functioning e.g. if they can tie shoe laces, whether they can read common social signs such as for toilets etc.)

3) There is also a set of photographs of people to look at and for you to say what ages the people are. There will also be a picture taken of you to help you decide which age group you feel you belong to.

After these things have been done, the results will be explained to you if you wish Also, there will be a report made to go in your medical file giving the results. You may read or have this report read to you and explained if you wish.

Once everyone in the study has done the same things, then all the results will be written about. We do this so that other people can learn about problems that people have in working out someone's age. Many people aren't very good at telling age and the results will help staff like me and the care staff who work with you, and it may help you. When the results are written about, they may be put in an article in a journal, but the results will be anonymous. Your name would not be in the article. Do you have any questions?

Major Research Project Paper

APPENDIX 3.3

AGE RECOGNITION STUDY

PATIENT CONSENT FORM

To be read / understood by patient

_____(mother, father, guardian) and_____ (name of member of care staff) have told me all about this study and I want to do it.

I will also be told how well I have done and the report will be put in my file.

I can stop if I want to.

This may be written about in a magazine but my name will not be printed.

Sign / mark here.....

Date.....

To be read and signed by a member of care staff

The details of this study have been read to or talked through with the above patient and s/he has understood what it means.

Sign here.....

Date.....

APPENDIX 4.1

Journal of Intellectual Disability Research

Information for contributors

Papers (in English) should be sent to the Editor, Journal of Intellectual Disability Research, University of Wales College of Medicine, Meridian Court, North Road, Cardiff CF4 3BL, Wales, UK. Papers are accepted on the understanding that they have not been and will not be published elsewhere. The original and two copies should be submitted to aid refereeing and these should be typed (with a wide margin), double spaced, on one side of standard paper (A4-30 × 21 cm). A title page should contain the author's name(s), place of work, address for correspondence, full title and short running title. Authors should retain one copy of the text, tables and illustrations as the editor cannot accept responsibility for damage or loss of manuscripts.

Page proofs must be returned to the Publisher within three days of receipt. Typographical errors and essential changes can be made at this stage. Major text alterations cannot be accepted. One free copy of the relevant issue will be distributed by the corresponding author to each co-author. Offprints may be purchased at prices determined by the Publisher by returning the form enclosed with page proofs.

The author should provide up to six keywords to aid indexing. Please note that 'intellectual disability', as used in JIDR, includes those conditions labelled mental deficiency, mental handicap, learning disability and mental retardation in some locales or disciplines.

Full reports of 1500–3000 words are suitable for major studies, integrative reviews and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions. Brief reports of 500–1500 words are encouraged, especially for replication studies, methodological research and technical contributions.

The text should proceed through sections of Abstract, Introduction, Materiais and Methods, Results and Discussion. Tables and figures should be submitted on separate sheets and referred to in the text together with an indication of their approximate position recorded in the text margin. The reference list should be in alphabetical order thus:

Giblett E.R. (1969) Genetic markers in Human Blood. Blackwell Scientific Publications, Oxford.

Moss T.J. & Austin G.E. (1980) Pre-atherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* 24, 137-41.

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

Spelling should conform to *The Concise Oxford Dictionary* of Current English and units of measurements, symbols and abbreviations with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units. Illustrations should be labelled with the figure number and author's name in soft pencil on the back identifying the top edge. Photographs should be glossy bromide prints of good contrast and well matched, preferably with a transparent overlay for protection. Colour photographs will be allowed only in special circumstances and the author will be asked to contribute towards the cost of reproduction. Line diagrams should be drawn with black ink on tracing paper or white card, or supplied as glossy prints. Papers may be judged to require extra-rapid publication by the Editor and referees.

The Journal welcomes the submission of accepted articles or 3.5" disk. Do not justify the lines of text. All disks must be accompanied by a hard copy of the paper together with details of the type of computer used, the software employed and the disk system, if known. Particular attention should be taken to ensure that any articles submitted in this form adhere exactly to journal style. Further details may be obtained from the Publisher.

Royal Society for Mentally Handicapped Children and Adults (MENCAP)

The Royal Society for Mentally Handicapped Children and Adults is the largest national organization exclusively concerned with people with intellectual disability and their families. The primary objective of the Society is to secure for intellectually disabled people provision commensurate with their needs. To this end, the Society aims to increase public knowledge and awareness of the problems faced by intellectually disabled people and their families, and thus create a sympathetic climate of public opinion as a necessary prerequisite of their acceptance into the community.

The Royal Society for Mentally Handicapped Children and Adults provides:

- through a network of Local Societies and Regional Offices support in all parts of the country;
- funds and support for research;
- specialist advisory and information services for the lay public and for professional workers;
- books and literature and, bi-monthly, the Journal of Intellectual Disability Research, Parents Voice and Viewpoint, MENCAP's new newspaper;
- an ongoing programme to facilitate the sharing of knowledge by means of symposia, conferences and information exchange;
- residential facilities for further education and for care and holidays;
- support for developing countries to scholarships and journal subscriptions.

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The Lord Rix CBE, DL, 123 Golden Lane, London, EC1Y ORT

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RSMHC & A is a registered charity, supported entirely by voluntary contributions. Applications for membership, or information, are invited by the Secretary General.

Major Research Project Paper

APPENDIX 4.2

PROTOCOL AND RAW RESULTS FORM

•	Name	Male/Female	•••••
٠	Date of Birth	********	
•	'How old are you?	?' Co	orrect?Yes/No
•	Current Address.	•••••••	•••••
•	Information leafle	et read Yes/No	
•	Permission/conser	ıt given	
	by client	Yes/No	
	by key staff	Yes/No	
	by G.P. or R.M.O	Yes/No	
٠	Periods of institut	ionalisationDates	Total time in institutions
	Total time in insti	tutions in years	•••
•	Currently living in	n institution?Yes/I	No
٠	VABS Total	*****	•••••
	Comm	unication	Age equivalence
	Daily l	Living Skills	Age equivalence
	Sociali	zation	Age equivalence
	Date tested	••••••	
٠	WAIS-R Full s	cale IQDate te	sted
•	Take photograph		
•	Test piece success	ful?Yes/No	
•	Age Identification	Test - Others (AIT-C	Others)(own sex photos first)
	MALE	FEMALE	
	1-4	1-4	
	2-5	2-5	
	3-6	3-6	> Score 1
	1-3	1-3	
	2-4	2-4	
	3-5	3-5	~
	4-6	4-6	> Score 2
	1-2	1-2	
	J-4 5 6	J-4 5 4	
		5-0 2 2	
	2-5 1_5	2-3 1.5	> Score 3
	4- J	4- J	- JUIT J

TOTAL AIT-Others SCORE.....

• Age Identification Test - Self (AIT-Self) Put age markers up, youngest to oldest, left to right. Put photographs of those the same sex as the participant under the appropriate headings.

Major Research Project Paper

APPENDIX 4.2 continued

Describe the age bands in order in words e.g. 'This is a photograph of someone who is between 0 and 4 years of age' etc.

Give the participant their own photograph and say, 'This is a photograph of you'.

Then ask, 'Show me someone who is the same age as you.'Take note of where the client puts the photograph or which photograph or band he or she indicates.

Client places self in which band 0-4

5-11 12-15 16-20 21-59 Is this correct older younger 60-90 Is this =, +1, +2, +3, -1, -2, -3 bands bands

 Index of Adulthood - Others (IA-Others) Shuffle the 12 cards (using both sexes) and show one card at a time, asking, 'Is this person a 'grown-up' or a child?' MALE

IVEL BEJEJ			A 4	TARY R	
1	2	3	1	2	3

4 5 6 4 5 6 Score.....

• Cues

Use tape recorder.

i)Ask, 'How can you tell how old a person is?' Also ask, 'How can you work out how old they might be?'. 'What sort of things give you an idea about how old someone is?'.....verbatim response transcribed

ii)Shuffle the 6 photographs of the same sex as the client

Offer one at a time, asking for each, 'Tell me what you can about this person......you can make up a little story that you think would be like them....you could say what they are like and the things that they like to do, where they might like to go.....'

Add in, 'Do they go to school sometimes?'

Allow enough time for the client to exhaust all his or her replies iii)For each of the above photographs say'

'I'm.....years old, you're.....years old' and ask, 'How old do you think this person is?'.....

Give photograph to participant to keep, with thanks



















Major Research Project Paper APPENDIX 4.4 SCORING SYSTEM FOR THE CUES MEASURE

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GENERAL CUES TO AGE

1 point	Mention of size, height, 'big'
1 point	Mention of gait
1 point	Mention of being able to tell from the activities in which they are involved, and, if examples are given, they must be expansive enough to encompass a wide age range
1 point	Comment on wrinkles, double chins, skin texture, facial lines or signs of ageing on the hands, such as gnarled, coarsening etc.
1 point	Understanding that there is a difference in clothes style over the years
1 point	Noticing the presence or absence of extra signs , such as wedding rings , make-up, jewellery, walking sticks, zimmer frames, push-chairs , prams etc
1 point	Hair colour, such as grey, white or absence of hair, bald or balding

0-4 YEARS

1 point	Mention of relationship to a carer referred to such as Mother, Father, Foster Mum etc., or living in Children's Home
1 point	Description of needing help for basic things like washing hands, combing hair, toiletting etc
1 point	Playing suitable games or enjoying child-like games such as dolls, teddy bears, toy cars, sweeties <i>or</i> sucking from a bottle, breast, having milk
1 point	Mention of attending a nursery or playgroup or similar
1 point	Mention of age-group, size - toddler, baby, wee, children or use of pram, pushchair etc
1 point	NOT at school

5 - 11 YEARS

1 point	Living with Mother or Father (or carer) or being in a Children's Home
1 point	Doing activities under supervision e.g. going on holiday <i>with</i> Mum and Dad, or helping Mum and Dad make the dinner or do the garden or go to the shops
1 point	Suitable activities, such as playing games, watching T.V., swings, chute, swimming, horse-riding, roller skating, bike, 'pictures', football, walking, dancing/disco, craftwork
Note:	Someone mentioning 'going with Mum to the swimming pool' would get 1 point for the pool <i>and</i> 1 point for going with Mum
1 point	Mention of school-type activities such as sums, writing, drawing, homework
1 point	Mention of social relationships such as playing with friends, boys, girls, pals
1 point	At school

12-15 YEARS

1 point	Mention of growing independence, getting more grown-up, not an adult but becoming one
1 point	Interest developing in sexual relationships, even if expressed just as wanting to meet/go out with boys/girls
1 point	Living at home , with Mother or Father , or in a care situation <i>or</i> if mention is made of supervision or of helping Mum or Dad with the shopping or the housework
1 point	Some mention is made of social relationships with peers
1 point	Suitable hobbies or interests are mentioned such as bikes, horses, TV, swimming, bowling, drama, going for a walk, outings, playing with computers
NOTE	Mention of going bowling with friends would therefore gain 2 points
1 point	At school

16 - 20 years

1 point	Mention of gaining employment or trying to gain employment, or of attending college or university, or of learning to become a nurse etc. If there is mention of unemployment then this would count. Mention of a specific job (if appropriate) would also qualify
1 point	Interest in developing sexual relationships , perhaps expressed as going dancing, going out for a drink with pals, going to a Youth Club, 'liking boys' etc
1 point	Living at home (or in care) and helping Mum or Dad or Carer but in an adult way or having or looking for own house or flat
1 point	Some mention of social activities such as going out with friends, having a bar lunch, joining the Church
1 point	Likely or possible hobbies - football, swimming, sports, snooker, T.V., bikes, 'pictures', discos etc
1 point	Left school or at college/ university or just starting first job, (or signing on)

21 - 59 years

1 point	Idea of the working years, or of being unemployed in these working years, earning a wage, mention of a specific job, such as 'looks like a nurse, gardener'
1 point	Relationships mentioned e.g. their wife, husband, children, partner or looking to have these relationships
1 point	Managing or assisting in household management , doing the dishes, cutting the grass, mending the car, cooking meals, cleaning the house
1 point	Mention of social activities such as meeting friends, going out with a partner or friend
1 point	Mention made of possible hobbies such as going to the pub, dancing, meal out.
1 point	Not at school

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Major Research Project Paper APPENDIX 4.4 continued

60 - 90 years

1 point	Mention of 'old', 'old lady', 'elderly', 'old folk's home', O.A.P.
1 point	Mention of a frailty or of possibly developing one in the future e.g. the use of sticks, a slower or difficult gait, changes to hearing or sight <i>or</i> comments such as 'getting on a bit' , 'needs to take things a bit easier', 'needs to rest more'
1 point	Mention of being retired , pension, O.A.P. <i>or</i> mention of a job suitable for someone who is 60+ e.g. business, doctor, shopkeeper (not an athlete)
1 point	Possible hobbies e.g. Bingo, listening to the radio, bowling, visiting parks, knitting, T.V. If dancing is mentioned, ensure that it is a likely style
1 point	Mention of household jobs needing to be done by the person or of someone helping the person with them
1 point	Not at school
NOTE	As long as the client has scored at least one point, <i>subtract</i> one point if mention is made of the person in the photograph having a Mother or Father alive, or of helping their Mum or Dad

Major Research Project Paper

APPENDIX 4.5

TRANSCRIPT OF AN AUDIO-TAPED INTERVIEW USING THE CUES MEASURE (to illustrate original material)

- Interviewer : How can you tell how old a person is?...How can you work out how old they might be?...What sort of things can give you an idea about how old someone is?
- Participant : Well, ah'm 64...
- Interviewer: So how can you tell how old someone is?
- Participant : Joan's 62 (Name changed to protect anonymity)
- Interviewer : So, how can you work it out?
- Participant :
- Interviewer: How do you work it out when you meet someone?
- Participant : Ah meet them.
- Interviewer: How do you tell how old I am?
- Participant : Ah don't know your age.
- Interviewer: How would you tell someone's age?
- Participant : You're a grown-up.
- Interviewer: How do you know that?
- Participant :
- Interviewer : I'm not a wee girl, am I?
- Participant : No, you're a grown-up...Are ye married?...Have ye a wee boy and girl?
- Interviewer: That's right. How do you tell from me what age I am?
- Participant : Ah cannae mind.
- Interviewer : So, how do you work it out?
- Participant : Ah bet you a pound you're sixty-odds.

Major Research Project Paper

APPENDIX 4.5 continued

- Interviewer : If you meet someone at the shops...if you meet someone when you're out..how do you tell how old they are?
- Participant :Well, that's very good. Ye ken ma home town, Dorothy? Ah comefrae Inverness.(Place name changed to protect anonymity)
- Interviewer : Do you?
- Participant : See, ah would like to.....
- Interviewer : What happens to your body as you get older?
- Participant: Ah'll no get bigger. See, ah'll stay the same size.
- Interviewer: Oh, has that got something to do with when you get older then?
- Participant : See, ah used tae go fur exercise, but it's no good, Dorothy, ye've got to keep moving.
- Interviewer: What happens when you get older?
- Participant : Ah'll no get ony taller.

Single Case Research Study 1 APPENDIX 5.1

BILD Publications, Frankfurt Lodge, Clevedon Hair, Victoria Road, Clevedon, Avon BS21 7SJ Tel: 01275 876519 Fax: 01275 343096

British Journal of Learning Disabilities

NOTES ON THE SUBMISSION OF MANUSCRIPTS

EDITORIAL POLICY AND GUIDELINES FOR AUTHORS

These guidelines are provided to assist authors in the preparation of manuscripts which conform to the BILD Publications house style. Failure to conform with these guidelines will inevitably delay the process of review and involve authors in additional work. We would, therefore, urge you to read through these notes carefully before submitting materials to *The British Journal of Learning Disabilities*.

AIMS OF THE JOURNAL

BJLD is a multi-disciplinary professional journal publishing articles which will draw the attention of those who are working in the field of learning disabilities to innovations in professional practice, to new ideas emerging from research, and to evaluations and reviews of on-going work which has general, professional relevance. Material submitted to BJLD should be original and any opinions expressed should be either supported by data or by well-reasoned arguments.

Reports on practice and research papers should be supported by descriptions of methodology and evidence which permits readers to evaluate the conclusions drawn. Reviews (commissioned or otherwise) should be supported by argument, data from relevant references and should place the review topic within the context of other developments in the field.

Submissions which are divided into two or more linked papers will only be accepted ir exceptional circumstances and when the subject matter clearly justifies this approach.

LAYOUT

Articles should be typed, double-spaced, on one side only of A4 paper, with a 1.5" margin of each side. Pages should be numbered consecutively in the top right-hand corner, commencing with the title page.

TEXT

The text should be written in the third person, in 'plain English', with an international, multi disciplinary readership in mind. Descriptions should be clear and concise and terminology spe cific to a particular profession should be explained for the benefit of people in other professions.

Care should be taken to use non-sexist language and, when referring to disabilities etc., t emphasise the person rather than the disability, so descriptions such as *people with learnin* disabilities should be used rather than the learning disabled. Clumsy expressions such as helshe he or she or slhe should be avoided, for example, by using the plural verb. Use the terr 'participants' to describe those involved in research rather than 'subjects'.

Single Case Research Study 1 APPENDIX 5.1 continued

Full references to the sources of all statistical measures used must be supplied.

If any technical terms specific to a particular profession are unavoidable, they must be explained briefly in the text immediately following. Statistical information should be translated into simple statements of significance, but the source of the measures used **must** be fully referenced and the full statistical data should be available from the main corresponding author.

COPIES

Four copies should be submitted, one of which should be the original typescript. One copy should be retained by the author.

LENGTH

Articles should not exceed 2,000 words (approximately eight pages of a double-spaced A4 typescript).

ORDER OF CONTENTS

Title Page

The title page should contain a short main title to indicate content and a sub-title if it is necessary to clarify this further

Authors

On a separate page include the first name and surname of each author, with details of their respective professional occupations and addresses. Where there is more than one author, indicate who should receive correspondence.

Summary

A concise 150 word summary should precede the main text. It should indicate the content and findings of the article.

Main Text

The main text should be presented in a logical sequence and be divided by appropriate subheadings.

Acknowledgements

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LENGTH

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Single Case Research Study 1 APPENDIX 5.1 continued

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Single Case Research Study II APPENDIX 6.1

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British Journal of Learning Disabilities

NOTES ON THE SUBMISSION OF MANUSCRIPTS

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AIMS OF THE JOURNAL

BJLD is a multi-disciplinary professional journal publishing articles which will draw the attention of those who are working in the field of learning disabilities to innovations ir professional practice, to new ideas emerging from research, and to evaluations and reviews of on-going work which has general, professional relevance. Material submitted to BJLD should be original and any opinions expressed should be either supported by data or by well-reasoned arguments.

Reports on practice and research papers should be supported by descriptions of methodology and evidence which permits readers to evaluate the conclusions drawn. Reviews (commissioned of otherwise) should be supported by argument, data from relevant references and should place the review topic within the context of other developments in the field.

Submissions which are divided into two or more linked papers will only be accepted in exceptional circumstances and when the subject matter clearly justifies this approach.

LAYOUT

Articles should be typed, double-spaced, on one side only of A4 paper, with a 1.5" margin of each side. Pages should be numbered consecutively in the top right-hand corner, commencin with the title page.

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Single Case Research Study II APPENDIX 6.1 continued

Full references to the sources of all statistical measures used must be supplied.

If any technical terms specific to a particular profession are unavoidable, they must be explained briefly in the text immediately following. Statistical information should be translated into simple statements of significance, but the source of the measures used **must** be fully referenced and the full statistical data should be available from the main corresponding author.

COPIES

Four copies should be submitted, one of which should be the original typescript. One copy should be retained by the author.

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Articles should not exceed 2,000 words (approximately eight pages of a double-spaced A4 typescript).

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Summary

A concise 150 word summary should precede the main text. It should indicate the content and findings of the article.

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APPENDIX 7.2

ADAPTED LOCKE-WALLACE MARITAL ADJUSTMENT TEST

(amended D. Bell, 1998)

. .

For full marking and scoring please see original paper by Locke and Wallace (1959)

I am going to ask you how you feel about things to do with your marriage.

1) Would you mark the line to show how happy you feel about your marriage?

The middle of the line is 'happy' and is how happy most people are in their marriage.

THIS side is if you are very UNhappy....and THIS side is if you are ABSOLUTELY happy. (Point to sides of line)

.

So, this side is unhappy, the middle is normal happiness and this side is absolutely happy.

APPENDIX 7.2 continued

a b c d e f Scale always almost always occasionally frequently almost always always agree agree disagree disagree disagree disagree

How much do you agree or disagree with ----- about

2) deciding what to buy, paying bills, spending on things for the house?

3) where to go for a night out, what things to do for fun, hobbies?

4) showing you care, touching, cuddling, saying loving things?

5) friends you have?

6) having sex or sexual touching?

7) what is the right thing to do, what you should do, how to behave?

8) what you want from life, what is the best way to live your life?

9) the way you deal with all your relations and in-laws?

10) When you have an argument or don't agree on something,

usually ----- gives in?

usually ----- gives in?

or do you agree together to 'give and take'?

APPENDIX 7.2 continued

11) Do you and do many things outside the house together?	
All of them	
Some of them	
Very few of them	
None of them	
12) When you're not working, do you prefer to	be
'always ' on the go', always busy	
OR to stay at home?	
Does prefer to be	
'always 'on the go'	
OR to stay at home?	
13) Do you ever wish you had not married?	
Frequently (lots of times)	
Occasionally (sometimes)	
Rarely (not often, now and again)	
Never	
14) If you started all over again, do you think	you would
marry the same person?	
marry a different person?	
not marry at all?	
15) Do you tell private or personal things	3
Almost never	
Rarely (not often, now and again)	
Most things	
Everything	

Single Clinical Research Study III APPENDIX 7.3 ADAPTED GOLOMBOK-RUST INVENTORY OF SEXUAL SATISFACTION (amended D. Bell 1998) MALE QUESTIONNAIRE

This questionnaire is a simpler version of the GRISS (Rust & Golombok, 1985). In brackets are even simpler phrases to use if necessary BUT PLEASE NOTE that sometimes the original GRISS question contains negatives which may be problematical for participants and where this happens the easier phrase in brackets in this adaptation may have the sentence turned around to avoid this. If this is the case, the set of asterisks *....* denotes the need to reverse the scoring when recording this on the score sheet.

See GRISS for full marking and scoring, and for details of transforming the scores. Briefly,

N = Never H = Hardly ever O = Occasionally U = Usually A = Always

1	Do you have sexual intercourse more than twice a week?	NHOUA
2	Do you find it hard to talk to about what you want her to	NHOUA
	do or not to do when you have sexual intercourse or sexual	
	touching (touching each other's private parts)?	
3	Do you feel aroused (really ready for sex) quite easily?	NHOUA
4	Can you slow down and put off your ejaculation during	NHOUA
	intercourse if you think you are going to 'come' too quickly?	
	(Can you slow down and put off 'coming' when you are having	
	sex if you think you are going to 'come' too quickly?)	
5	Are you sad that there is not enough variety (different ways	NHOUA
	to have sex) in your sex life with?	

APPENDIX 7.3 continued

6 Do you not enjoy stroking and touching's genitals (or use	NHOUA
colloquial word known)? (*Do you like stroking and touching	
's genitals (or use colloquial word known)?*)	
7 Do you get tense and nervous when wants to have sex?	NHOUA
8 Do you enjoy having sex with?	NHOUA
9 Do you ask what she likes or doesn't like about sex and	NHOUA
touching each other's private parts?	
10 Do you not manage to get an erection (or use colloquial	NHOUA
word known)? (* Do you get an erection?*)	
11 Do you think there's not enough love and caring in your	NHOUA
sexual relationship?	
12 Do you like stroking and touching your penis?	NHOUA
13 Can you manage not to ejaculate ('come') too quickly when	NHOUA
when you're having sex?	
14 Do you try and avoid having sex with?	NHOUA
15 Is your sexual relationship with fine?	NHOUA
16 Do you get an erection (or use colloquial word known) while	NHOUA
you and are having foreplay (touching each other's private	
parts before you have sex)?	
17 Are there weeks when you don't have sex at all?	NHOUA
18 Do you both enjoy masturbating (or use colloquial word	NHOUA
known) each other?	
19 If you want sex with do you show her or tell her you	NHOUA
want it?	
20 Do you not liked being cuddled and touched by?	NHOUA
(*Do you like being cuddled and touched by?*)	
21 Do you have sex as often as you would like to?	NHOUA

APPENDIX 7.3 continued

22 Do you ever say no if wants sex?	NHOUA
23 Does your erection (or use colloquial word known) go	NHOUA
down while you're having sex?	
24 Do you ejaculate ('come') before you want to almost as	NHOUA
as soon as your penis goes into's vagina (or use	
known colloquial words)?	
25 Do you enjoy cuddling and stroking's body?	NHOUA
26 Do you feel that you're not interested in sex?	NHOUA
27 Do you ejaculate ('come') by accident just before	NHOUA
your penis goes into's vagina (or use known	
colloquial words)?	
28 Do you feel bad about what you both do when you're	NHOUA
having sex?	

APPENDIX 7.3 continued

GRISS QUESTIONNAIRE Female, Amended D. Bell, 1998

N.B. * = reverse scoring

N = Never	H = Hardly ever	O = Occasionally U	J = Usua	ally $A = A$	lways
1 Do you feel	that you're not inter	rested in sex?	1	NHOUA	
2 Do you ask	what he likes or	r doesn't like about sex ar	nd l	NHOUA	
touching each	other's private parts	?			
3 Are there w	eeks when you don'	t have sex at all?	ſ	NHOUA	
4 Do you feel	aroused (really read	ly for sex) quite easily?	1	NHOUA	
5 Are you hap	ppy with the time yo	u and spend touching	1	NHOUA	
each other's p	rivate parts?		·		
6 Is your vagi	na so tight that	can't get his penis in? (or	1	NHOUA	
use colloquial	word known)				
7 Do you try t	to avoid having sex	with?	1	NHOUA	
8 Do you have	e an orgasm ('come') when you are with?	נ י	NHOUA	
9 Do you enjo	y cuddling and strol	king's body?	1	NHOUA	
10 Is your sex	ual relationship with	fine?	1	NHOUA	
11 Can you pu	it your finger into yo	our vagina (or use colloqui	ial 1	NHOUA	
word known)	without any difficult	y?			
12 Do you not	like stroking and to	uching's penis (or us	e l	NHOUA	
colloquial wor	rd known) (*Do you	like stroking and touching	g		
's penis?*))				
13 Do you get	tense and anxious w	when wants sex?	1	NHOUA	
14 Do you find	d it impossible to ha	ve an orgasm (or use collo	oquial 1	NHOUA	
word known)?	' (*Do you have orga	usms?*)			

APPENDIX 7.3 continued

15 Do you have sex more than twice a week? NHOUA

16 Do you find it hard to talk to about what you want him	NHOUA
to do or not to do when you have sexual intercourse or sexual	
touching? (touching each other's private parts)	NHOUA
17 Can get his penis into your vagina without you feeling	NHOUA
sore or uncomfortable (or use colloquial words known)?	
18 Do you think there's not enough love and caring in your	NHOUA
sexual relationship?	
19 Do you enjoy having your genitals (or use colloquial word	NHOUA
known) stroked and touched by?	
20 Do you ever say no when wants sex?	NHOUA
21 Do you have an orgasm (or use colloquial word known)	NHOUA
when strokes your clitoris (private parts) when you are having	Ş
foreplay (touching each other sexually before you have sex)?	
22 Are you unhappy about the time spends on sexual	NHOUA
intercourse itself? (*Do you think spends enough time	
on sex itself?*)	
23 Do you feel bad about what you both do when you're	NHOUA
having sex?	
24 Do you think your vagina (or use colloquial word known) is	NHOUA
too small so that's penis (or colloquial word) can't get in	
very far?	
25 Do you not like being cuddled and touched by? (*Do you	NHOUA
like being cuddled and touched by?*)	
26 Does your vagina (or use colloquial word known) get moist	NHOUA
(wet) and slippery when you are touching or making love?	

APPENDIX 7.3 continued

27 Do you enjoy having sex with?	NHOUA
28 Do you not have an orgasm during intercourse? (*Do you	NHOUA
have an orgasm during intercourse?*)	

	-
CLASGOW	1
CULT	V
Literatio	