

The HARC
Challenging
Behaviour Project

Report
2

The Prevalence of
Challenging Behaviour

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Report 2

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In 1994 the Department of Health commissioned the Hester Adrian Research Centre at the University of Manchester to undertake a series of inter-linked projects to investigate various aspects of 'challenging' behaviours shown by people with learning disability. These projects extended work previously undertaken at the Hester Adrian Research Centre. In particular they built upon a large-scale epidemiological study of the prevalence of challenging behaviour undertaken in the areas served by seven District Health Authorities in the North West of England in 1988 (see Kiernan & Qureshi, 1993; Qureshi, 1991/2, 1993, 1994; Qureshi & Alborz, 1992).

The aims of these projects were to investigate the:

- persistence and emergence of challenging behaviours;
- prevalence of challenging behaviours;
- experience and views of people with challenging behaviour;
- experience and views of informal carers of people with challenging behaviour who are living at home;
- treatment and management of challenging behaviour;
- costs of services for people with challenging behaviour.

The results of the project are summarised in seven separate reports.

- Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Hatton, C., Mason, H., Swarbrick, R., Mason, L., Smith, K., Wright, K., Manion, R., Ferguson, B., & Hennessey, S. (1997). *The HARC Challenging Behaviour Project. Summary Report*. Manchester: Hester Adrian Research Centre, University of Manchester.
- Kiernan, C., Reeves, D., Hatton, C., Alborz, A., Emerson, E., Mason, H., Swarbrick, R., & Mason, L. (1997). *The HARC Challenging Behaviour Project. Report 1: Persistence and Change in the Challenging Behaviour of People with Learning Disability*. Manchester: Hester Adrian Research Centre, University of Manchester.
- Emerson, E., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., Kiernan, C., & Mason, L. (1997). *The HARC Challenging Behaviour Project. Report 2: The Prevalence of Challenging Behaviour*. Manchester: Hester Adrian Research Centre, University of Manchester.
- Mason, H., Swarbrick, R., & Emerson, E. (1997). *The HARC Challenging Behaviour Project. Report 3: User Perspectives*. Manchester: Hester Adrian Research Centre, University of Manchester.
- Kiernan, C., Alborz, A., Mason, H., Swarbrick, R., Mason, L., Reeves, D. & Emerson, E. (1997). *The HARC Challenging Behaviour Project. Report 4: Experience and Views of Parents Caring for People with Learning Disability Living in the Family Home*. Manchester: Hester Adrian Research Centre, University of Manchester.
- Emerson, E., Alborz, A., Kiernan, C., Mason, H., Reeves, D., Swarbrick, R., & Mason, L. (1997). *The HARC Challenging Behaviour Project. Report 5: The Treatment & Management of Challenging Behaviour*. Manchester: Hester Adrian Research Centre, University of Manchester.
- Smith, K., Mannion, R., Ferguson, B., & Hennessey, S. (1996). *Challenging Behaviour: The Costs of Service Provision*. York: Centre for Health Economics, University of York.

Copies of the first six of these reports are available from the Hester Adrian Research Centre, University of Manchester, Manchester M13 9PL. Copies of the seventh report are available from The Centre for Health Economics, University of York, York, YO1 5DD.

The aim of this report is to present new data from a total population survey of the prevalence of challenging behaviour and the prevalence of specific types of challenging behaviours. It will also, through the use of correlational methods, attempt to identify some personal and environmental characteristics associated with people being at increased 'risk' of showing challenging behaviour.

The Overall Prevalence of Challenging Behaviours

Relatively few studies have attempted to identify the prevalence of multiple forms of challenging behaviour among a total population sample (i.e. all people with learning disability living in a defined area). More commonly, studies have focused on either specific topographically defined sub-types of challenging behaviour, such as self-injurious behaviour (e.g. Oliver, Murphy & Corbett, 1987) or aggression (e.g. Harris, 1993), or have restricted sampling to specific sub-populations of people with learning disability, for example those living in institutional settings (e.g. Griffin et al, 1987), community settings (e.g. Rojahn, 1986) or children attending schools (e.g. Kiernan & Kiernan, 1994).

As noted above, the Hester Adrian Research Centre undertook a large-scale study of the prevalence of challenging behaviour in the areas served by seven District Health Authorities in the North West of England in 1988 (see Kiernan & Qureshi, 1993; Qureshi, 1991/2, 1993, 1994; Qureshi & Alborz, 1992). This study screened approximately 4,200 people with learning disability and identified people as showing *severe* challenging behaviours if they had either:

- at some time caused more than minor injury to themselves or others, or destroyed their immediate living or working environment; or
- showed behaviours at least once a week that required the intervention of more than one member of staff to control, or placed them in danger, or caused damage which could not be rectified by care staff, or caused more than one hour's disruption;
- or showed behaviours at least daily that caused more than a few minutes disruption.

Using this definition, 1.91 people per 10,000 of the general population (range 1.41 to 2.55 per 10,000 across the seven areas) were identified as having a learning disability and severe challenging behaviour. This translates to an estimated prevalence rate of 5.7% of all people within these areas who had been administratively defined as having a learning disability. More recently, Emerson and Bromley (1995), using closely parallel methods in another area of North West England, identified 3.33 people per 10,000 of the general population as having a learning disability and severe challenging behaviour (equivalent to approximately 7.8% of the people with learning disability who were screened).

The Prevalence of Specific Forms of Challenging Behaviours

Studies which have focused on the prevalence of particular forms of challenging behaviour provide a more detailed breakdown of topographical variants of general classes of challenging behaviours. Harris (1993), for example, reports that the most prevalent forms of aggression shown in the past month by 168 people with learning disability identified in one administratively defined area were: punching, slapping, pushing or pulling (51% of people showing aggression); kicking (24%); pinching (21%); scratching (20%); pulling hair (13%); biting (13%); head butting (7%); using weapons (7%); choking, throttling (4%).

Similarly, Oliver et al, (1987) reported that the most common topographies of self-injurious behaviour shown by 596 people with learning disability identified through a total population survey carried out in the South East Thames Regional Health Authority were: skin picking (39%); self-biting (38%); head punching/slapping (36%); head to object banging (28%); body to object banging (10%); other (10%); hair removal (8%); body punching or slapping (7%); eye poking (6%); skin pinching (4%); cutting with tools (2%); anal poking (2%); other poking (2%); banging with tools (2%); lip chewing (1%); nail removal (1%); teeth banging (1%).

It should be noted that, in both studies, the totals add up to more than 100% due to the co-occurrence of different forms of challenging behaviour in the same individual. Thus, in the Kiernan, Qureshi and Alborz survey, 43% of the people identified as showing challenging behaviour which were rated as presenting a serious management problem did so in two or more of the four possible areas of aggression, self-injury, property destruction and 'other' behaviour (Qureshi, 1994). Similarly, Murphy et al (1993) report that, of the people with self-injurious behaviour identified in the South East Thames Regional Health Authority study who wore protective devices, 40% showed physical aggression and 36% property destruction.

In addition to the co-occurrence of challenging behaviour across broadly defined categories, people are also likely to show multiple forms of challenging behaviour within categories. Thus, for example, Oliver et al (1987) report that 54% of the people identified as showing self-injurious behaviour engaged in more than one form of self-injury. Indeed, 3% (20 of the 596) engaged in five or more different forms of self-injury. This rose to 7% for people whose self-injury was sufficiently severe to justify the use of protective devices (Murphy et al, 1993).

Personal and Environmental Risk Factors

A number of studies have employed correlational methods to identify personal and environmental factors which are associated with an increased prevalence of challenging behaviour. Provided below, is a brief summary of this evidence.

Gender

In general, boys and men are more likely to be identified as showing challenging behaviour than girls and women. This relationship appears to be more pronounced:

- for aggression and property destruction than for self-injury (Borthwick-Duffy, 1994; Johnson & Day, 1992; Oliver et al, 1987; Rojahn, 1994);
- in institutional settings (Qureshi, 1994);
- for more severe challenging behaviour (Kiernan & Kiernan, 1994).

There is, however, some evidence to suggest that women may be more likely to show multiple topographies of self-injurious behaviour (Maurice & Trudel, 1982; Maisto, Baumeister & Maisto, 1978).

Age

The overall prevalence of challenging behaviours increases with age during childhood, reaches a peak during the age range 15-34 and then declines (e.g. Borthwick-Duffy, 1994; Kiernan & Kiernan, 1994; Oliver et al, 1987; Rojahn, 1994). When comparisons are made with the age structure of the total population of people with learning disability it is apparent that challenging behaviours appear to be particularly over-represented in the 15-24 age group (Kiernan & Qureshi, 1993). This progression is more complicated, however, when the prevalence of particular forms of challenging behaviour is examined. Oliver et al (1987), for example, report that while multiple topographies, head to object banging, head punching and finger chewing are significantly more prevalent in younger people with self-injurious behaviour, skin picking and cutting with tools are more prevalent among older people.

Specific Syndromes and Disorders

An increase in the prevalence of some particular forms of challenging behaviour has been reported to occur in association with specific syndromes associated with learning disability. These include:

- ❑ occurrence of self-injurious behaviour, specifically hand and lip biting, among *all* people who have Lesch-Nyhan syndrome (Harris, 1992; Nyhan, 1994);
- ❑ very high prevalence of self-injurious hand-wringing in Rett syndrome (Harris, 1992);
- ❑ greater than expected prevalence of various forms of self-injurious behaviour in the Cornelia de Lange, Riley-Day and Fragile-X syndromes (Harris, 1992);
- ❑ greater than expected prevalence of hyperkinesia, attention deficits and stereotypy in Fragile-X syndrome (Borghgraef et al, 1990; Lachiewicz, Spiridigliozzi, Gullion, Ransford & Rao, 1994);
- ❑ very high prevalence of food-related challenging behaviours in Prader-Willi syndrome (Murphy, 1994).

In addition, an increased prevalence of challenging behaviour has been reported among people with epilepsy, both in general (cf Kiernan & Kiernan, 1994) and in relation to specific forms of epilepsy (e.g. Gedye, 1989).

Level of Intellectual Impairment

In general, the prevalence of aggression, property destruction, self-injurious behaviour and other forms of challenging behaviours are positively correlated with degree of intellectual impairment (e.g. Borthwick-Duffy, 1994; Johnson & Day, 1992; Kiernan & Kiernan, 1994; Kiernan & Qureshi, 1993; Oliver et al, 1987; Oliver, 1993; Qureshi, 1994; Rojahn, 1994). Thus, for example, among service users in California, 7.6% of people with mild mental retardation, 13.6% of people with moderate mental retardation, 22.0% of people with severe mental retardation and 32.9% of people with profound mental retardation showed one or more form of challenging behaviour (Borthwick-Duffy, 1994). People with more severe intellectual impairment are also likely to show multiple forms of challenging behaviour (Borthwick-Duffy, 1994; Oliver et al 1987; Rojahn, 1986, 1994) and, if self-injurious, are more likely to be restrained (Oliver et al, 1987).

Additional Disabilities

In addition to the overriding effects of level of intellectual impairment, challenging behaviours are more likely to be seen in people who:

- ❑ have additional impairments of vision or hearing (e.g. Kiernan & Kiernan, 1994; Maisto, Baumeister & Maisto, 1978; Schroeder, Schroeder, Smith & Dalldorf, 1978);
- ❑ are non-verbal or who have particular difficulty with receptive or expressive communication (e.g. Borthwick-Duffy, 1994; Kiernan & Kiernan, 1994; Schroeder et al, 1978);
- ❑ are reported to have periods of disturbed sleep (Kiernan & Kiernan, 1994);
- ❑ have mental health problems (e.g. Borthwick-Duffy, 1994).

Self-injury, in particular, is markedly more prevalent among people with severe learning disability who have significant impairments of mobility (Kiernan & Kiernan, 1994; Kiernan & Qureshi, 1993).

Setting

The prevalence of challenging behaviour is also positively related to the level of restrictiveness in the person's residential placement (Borthwick-Duffy, 1994; Bruininks, Olson, Larson and Lakin, 1994; Emerson, 1992; Johnson & Day, 1992; Harris, 1993). Again, data from a survey of service users in California indicate that 3.0% of people living independently, 8.0% of people living with their families, 8.8% of people living in smaller (1-6 place) community facilities, 24.4% of people living in larger community-based facilities and 48.8% of people living in institutions were identified as showing one or more forms of challenging behaviour (Borthwick-Duffy, 1994).

The interpretation of the relationship between setting and challenging behaviour is problematic due to the important role played by challenging behaviour in increasing the risk of admission and re-admission to more restrictive settings (Borthwick-Duffy et al, 1987; Eyman and Call, 1977; Hill & Bruininks, 1984; Intagliata & Willer, 1982; Lakin et al, 1983; Schalock et al, 1981). Indeed, since studies of the effects of deinstitutionalisation have failed to identify any consistent effects on a move to less restrictive settings on challenging behaviour reported by key informants (see Emerson & Hatton, 1994; Hatton & Emerson, 1996; Larson & Lakin, 1989), it would appear that such behaviours lead to institutionalisation, rather than institutional environments leading to challenging behaviour.

The information presented in this report is a total population survey undertaken in two localities defined by relevant 1988 District Health Authority boundaries. For purposes of comparison, data will also be presented from the 1988 study undertaken by the Hester Adrian Research Centre (Kiernan & Qureshi, 1993; Qureshi, 1994; Qureshi & Alborz, 1992). A summary of the relevant procedures is presented below.

Sampling

In 1988 seven District Health Authorities in the area then covered by the North West Regional Health Authority participated in our previous total population survey of the extent and nature of challenging behaviours amongst people with learning disability (see Kiernan & Qureshi, 1993; Qureshi, 1994; Qureshi & Alborz, 1992). Two of these seven areas agreed to repeat this exercise in 1995. The total population survey entailed a three stage process.

First, interviewers from the Hester Adrian Research Centre identified all services for people with learning disability within these two districts. This included all residential, day, respite and peripatetic services provided by the statutory (education, health and social services) and independent sector within the area coterminous with 1988 District Health Authority boundaries. In addition, a register was constructed of all people with learning disability identified by staff across agencies as receiving a service outside the district.

Second, a *Setting Interview* (Kiernan & Qureshi, 1986) was used to screen all people within each service setting for the presence of challenging behaviour. Settings included:

- 3 NHS learning disability hospitals;
- 1 regional medium secure unit;
- 1 assessment and treatment centre;
- 19 staffed houses (5 operated by NHS Trusts, 7 by Local Authority Social Services Departments, 7 by organisations in the independent sector);
- 10 hostels (6 operated by Local Authority Social Services Departments, 4 by organisations in the independent sector);
- 1 village community;
- 7 day centres (all operated by Local Authority Social Services Departments);
- 1 special needs unit operated by an independent sector organisation;
- 1 horticultural project;
- 3 adult placement services;
- 4 nurseries;
- 14 educational establishments;
- 12 other services (primarily peripatetic support teams);
- 12 residential facilities, 1 residential school and 4 day services located outside of the two areas.

Overall this involved screening approximately 2,200 people with learning disability.

The Setting Interview involved collecting general information about the service being screened (e.g. type of service, agency responsible, number of places, number of service users - long term and/or short term - number of male and female users) and then identifying whether in the past month there were any users who were challenging to the service. Identification was achieved through asking questions on:

- physical features of the setting that were designed to prevent or reduce damage to individuals or equipment;
- service users who had injured themselves or others in the last month, as well as, whether any users had caused themselves or others serious injury more than a month ago and were still considered likely to do so;
- parts of the facility which were locked to prevent access or prevent people going out of the building and who would otherwise be in difficulty;
- individuals who caused themselves problems or extra work for staff by their behaviour outside the setting;
- individuals using the service who reduced the quality of life for other service users.

The names of the people mentioned within each setting were summarised and the informant was asked if there was any person missed who they felt should have been identified and why.

The inter-rater and inter-informant reliability of the screening process was established as part of the 1988 study (Qureshi & Alborz, 1992). Two exercises were undertaken, one in Social Services settings and the other in a long-stay hospital. In both exercises the screening process was repeated by a different interviewer with a different member of staff in the same setting. In eight Social Services settings interviews covered approximately 280 service users. The full two stage identification process was undertaken by completion of Individual Schedules for people identified by the Setting Interview during the screening process. In the hospital there were parallel interviews on ten wards housing 167 people. The likely number who would have been eliminated at the second stage, through their not reaching criterion levels on the Individual Schedule, was estimated from the actual figures obtained in the 1988 survey. The screening process achieved acceptable levels of reliability, Cohen's Kappa being estimated as 0.71 in Social Services settings and 0.62 in hospitals (Cohen, 1960).

Finally, the interviewer went through a copy of the '*Individual Schedule*' with the informant for one of the people identified (Alborz et al, 1994). If more than one person was identified, additional copies of this questionnaire were left with the member of staff for completion and collection at a later date.

This means of identifying people with learning disability who show challenging behaviour was designed to be over inclusive in the first instance. *The criteria for inclusion within the final sample was that the informant rated the person as showing challenging behaviour which presented a serious management problem or would do were it not controlled within that setting.* Fifteen Individual Schedules were excluded from the final sample as they did not meet this criteria.

Data Collection

The Individual Schedule collected information in three broad sections.

Part One collected information on the such personal characteristics as age, gender, ethnicity, marital status, residence and day-time occupation. In addition, information was collected on:

- a brief description of their residential and day service history since 1988;
- the person's level of physical and intellectual functioning, as well as self care, domestic and social skills;
- the presence of a diagnosis of autism or other mental health problem;
- the occurrence of stereotypic behaviours.

In the 1988 project pairs of Schedules were available from different settings for 116 people. Similarly, in 1995, pairs of Schedules were available from different settings for 48 people. Analyses of these data confirmed that items such as those concerning key variables like mobility, expressive and receptive communication (and the index of communicative ability), the self-care index, and occurrence and frequency of seizures, all achieved satisfactory levels of reliability (correlations ranging from 0.76 to 0.89). Other variables, including reading, writing, use of money, and appropriate social behaviour with people well known and strangers, also reached satisfactory levels of reliability (correlations ranging from 0.67 to 0.76).

Part Two contained four colour-coded sections relating to aggressive, self-injurious, destructive and 'other' difficult, disruptive or socially unacceptable behaviour. Informants were instructed to complete these sections if the person showed that form of challenging to the extent that it was considered by the key informant to constitute a serious management problem or would do were it not for specific controlling measures undertaken in the person's current setting. Each section collected information on:

- the specific form of the challenging behaviour, its frequency, circumstances and level of intervention required to deal with incidents;
- reactive strategies employed to manage episodes of challenging behaviour;
- treatment programmes employed to prevent or reduce the occurrence of the person's challenging behaviour;
- the consequences of the behaviour for the person themselves, staff and other service users in terms of physical injury, as well as whether the person puts themselves in physical danger;
- the emotional reactions of staff and other residents to the behaviour;
- staff beliefs about the causes of the behaviour.

Part Three of the questionnaire addressed general aspects of the person's challenging behaviour and included questions on:

- the perceived level and nature of demands placed upon staff;
- the overall frequency of challenging behaviour;
- the general consequences of the person's challenging behaviour in relation to disruption to the setting, work for staff and affect on the activities of the person;
- staff opinions regarding the appropriacy of the setting and the effectiveness of the service provided within the setting;
- sources of stress for staff;
- case management and keyworking arrangements;
- behavioural treatment;
- medication;
- contact with professional and support staff.

Finally, information was sought on mental health status through completion of the PAS-ADD checklist (Moss et al, 1996). This screening instrument has been devised to help people caring for a person with learning disability to ascertain whether they might be suffering a mental health problem. Information was sought on:

- the relationship of the respondent to the person in question and the length of time they had known them;
- significant or traumatic events which may have occurred in the person's life in the previous year;
- changes in the person's behaviour which have been apparent in the last four weeks.

The Individual Schedule was completed as an interview, where necessary, but was otherwise left in the setting for completion by a staff member who knew the person well. Members of the research team were available for consultation by telephone should staff have difficulty in interpreting items in the Schedule. Completed Schedules were either collected by members of the team or returned by post.

After receipt, Schedules were checked to ensure that all relevant items had been completed. Data from the Schedules were then coded and entered in to an SPSS data-base. The 1995 data-base was then merged with the 1988 data-base to allow longitudinal analyses to be undertaken.

A number of indices were developed from data in the Individual Schedule to facilitate analysis. These included indices relating to communication skills, self-help skills, and staff stress. Other indices brought together ratings of consequences and levels of intervention within and across the four categories of challenging behaviour. For example, separate ratings of severity of each category of challenging behaviour were derived from five items relating to each category. This approach maximised use of information provided and enhanced the sensitivity of analyses.

In the following sections we will present results relating to the:

- overall prevalence of challenging behaviour;
- prevalence of specific forms of challenging behaviour;
- relationships between different forms of challenging behaviour;
- characteristics of the people identified as showing challenging behaviour;
- relationships between personal characteristics and specific forms of challenging behaviour.

Throughout these sections we will draw comparisons between people showing 'less' or 'more' demanding challenging behaviour. The derivation of these categories is described in detail in Report 1 in this series (Kiernan et al, 1997b). Briefly, people who show **more demanding** challenging behaviour met *at least one* of the following four criteria:

- they showed challenging behaviour *at least once a day*;
- their challenging behaviour *usually* prevented the person from taking part in programmes or activities appropriate to their level of ability;
- their challenging behaviour *usually* required the physical intervention by one or more members of staff;
- their challenging behaviour *usually* led to major injury (ie injury requiring hospital treatment) to either the person themselves, carers or other people with learning disability.

People who show **less demanding** challenging behaviour will not meet any of the above criteria but will still show challenging behaviour which informants regard as constituting a serious management problem or would to were it not for specific controlling measures undertaken in the person's current setting..

The Overall Prevalence of Challenging Behaviour

The 1995 survey identified a total of 264 people across the two localities who showed challenging behaviour. In Table 1, below, we present these data as overall prevalence rates based on the total (general) population and as prevalence rates based on the population of people with learning disability screened. We also present, for purposes of comparison, a re-analysis of data collected in the 1988 study.

District	Population (000s)	Number Screened	Administrative Prevalence of Learning Disability (1)	Number of People With Challenging Behaviour Identified	Overall Prevalence (per 100,000 of base population)	Overall Prevalence (as % of people with learning disability screened)
1988						
A	266.9	603	0.23%	93	34.8	15.4%
B	234.1	806	0.34%	137	58.5	17.0%
C	141.8	539	0.38%	93	65.6	17.3%
D	290.5	663	0.23%	113	38.9	17.0%
E	132.5	410	0.31%	71	53.5	17.3%
F	265.3	698	0.26%	115	43.3	16.5%
G	200.2	481	0.24%	72	36.0	15.0%
A&G	467.1	1,084	0.23%	165	35.3	15.2%
Total	1,531.3	4,200	0.27%	694	45.3	16.5%
1995						
A	266.9	1,255	0.47%	154	57.7	12.3%
G	200.2	934	0.47%	110	54.9	11.8%
A&G	467.1	2,189	0.47%	264	56.5	12.1%
Notes:	(1)	Administrative prevalence is defined as the percentage of the total population screened (i.e. identified as having a learning disability)				

As can be seen, if comparisons are restricted to the two localities (A and G) in which data was collected in both 1988 and 1995, the above data represent a 60% increase in the number of people identified as showing challenging behaviour. These increases are reflected in increased prevalence rates calculated on the basis of rate per 100,000 of the general population.

It is also notable, however, that just over twice as many people with learning disability were screened in localities A and G in 1995 when compared with 1988. Thus, while the absolute numbers of people identified as showing challenging behaviour increased, the per cent of people screened who showed challenging behaviour decreased from 15.2% to 12.1%.

It appears plausible to suggest that the much more thorough screening operation undertaken in 1995 extended the survey to populations (e.g. pre-school children) in which there were proportionally fewer people with challenging behaviour.

Sixty four per cent of people identified showed more demanding challenging behaviour.

Types of Challenging Behaviour

Table 2, below, presents information on the prevalence of the broad categories of aggression, self-injury, destructive and ‘other’ forms of challenging behaviour. An individual was identified as showing a general category of challenging behaviour if informants rated behaviour in that category as constituting a serious management problem or as being likely to constitute a serious management problem were it not for specific measures undertaken in the present setting to control the behaviour.

		among people identified as showing challenging behaviour	among people identified as showing <i>more demanding</i> challenging behaviour
	form of challenging behaviour		
1988 (7 localities)			
	aggression	41.8%	41.2%
	self-injury	27.2%	29.5%
	destructive behaviour	30.3%	32.7%
	other challenging behaviour	71.9%	75.6%
	one general form	49.1%	44.7%
	two general forms	33.3%	34.2%
	three general forms	14.8%	17.4%
	all four general forms	2.7%	3.6%
1995 (2 localities)			
	aggression	58.3%	64.4%
	self-injury	28.0%	32.6%
	destructive behaviour	33.0%	37.9%
	other challenging behaviour	81.4%	80.3%
	one general form	39.4%	33.3%
	two general forms	29.9%	28.0%
	three general forms	23.5%	30.3%
	all four general forms	7.2%	8.3%

As can be seen, while the numbers of people screened increased between 1988 and 1995, the prevalence of self-injury and destructive behaviours *among people identified as showing challenging behaviour* remained fairly constant. Multiple forms of challenging behaviour were more common among people identified as showing more demanding challenging behaviour in 1988 ($\chi^2 = 13.52$, $df = 3$, $p < 0.01$) and 1995 ($\chi^2 = 8.01$, $df = 3$, $p < 0.05$).

In Table 3, information is presented on the specific forms of aggression, self-injury and ‘other’ forms of challenging behaviour shown by children (all people aged below 19 years of age) and adults in the 1995 sample (specific topographies of destructive behaviours were not investigated). As above, an individual was identified as showing a specific form of challenging behaviour if informants rated behaviour in that category as constituting a serious management problem or as being likely to constitute a serious management problem were it not for specific measures undertaken in the present setting to control the behaviour.

Table 3: Prevalence of Specific Topographies of Challenging Behaviour in 1995				
general form		prevalence among people identified as showing challenging behaviour	prevalence among adults identified as showing challenging behaviour	prevalence among children identified as showing challenging behaviour
aggression		58.3%	58.0%	59.3%
	specific topographies	prevalence among people identified as showing serious or controlled aggression	prevalence among adults identified as showing serious or controlled aggression	prevalence among children identified as showing serious or controlled aggression
	hitting others with hands	74.7%	72.4%	77.6%
	verbal aggression	60.4%	58.6%	62.7%
	hitting others with objects	40.9%	36.8%	46.3%***
	meanness/cruelty	34.4%	23.0%	49.3%
	scratching others	26.6%	20.7%	34.3%
	pulling others hair	23.4%	20.7%	26.9%
	pinching others	20.1%	16.1%	25.4%
	biting others	16.2%	18.4%	13.4%
	other forms of aggression	7.8%	9.2%	6.0%
general form		prevalence among people identified as showing challenging behaviour	prevalence among adults identified as showing challenging behaviour	prevalence among children identified as showing challenging behaviour
destructive behaviour¹		33.0%	30.0%	37.2%*
Note: ¹ no information was collected on specific forms of destructive behaviours * indicates difference between child and adults $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$				
general form		prevalence among people identified as showing challenging behaviour	prevalence among adults identified as showing challenging behaviour	prevalence among children identified as showing challenging behaviour
self-injurious behaviour		28.0%	28.0%	28.3%
	specific topographies	prevalence among people identified as showing serious or controlled self-injury	prevalence among adults identified as showing serious or controlled self-injury	prevalence among children identified as showing serious or controlled self-injury
	hitting head with hand/body part	47.3%	46.9%	47.6%
	biting self	44.6%	40.5%	50.0%
	hitting head with/against objects	41.9%	40.5%	43.8%
	hitting body with hand/body part	35.1%	38.1%	31.3%
	hitting body with/against objects	27.0%	26.2%	28.1%
	self-scratching	20.3%	14.3%	28.1%
	self-pinching	18.9%	19.0%	18.8%
	eating inedible objects	18.9%	21.4%	15.6%
	stuffing fingers in body openings	12.2%	11.9%	12.5%
	excessive drinking	10.8%	16.7%	3.1%

Table 3: Prevalence of Specific Topographies of Challenging Behaviour in 1995				
	hair pulling	10.8%	11.9%	9.4%
	other forms of self-injury	9.5%	11.9%	6.3%
	teeth grinding	6.8%	7.1%	6.3%
	self-induced vomiting	4.1%	2.4%	6.3%
	air swallowing	1.4%	2.4%	0.0%
	general form	prevalence among people identified as showing challenging behaviour	prevalence among adults identified as showing challenging behaviour	prevalence among children identified as showing challenging behaviour
	'other' challenging behaviour	81.4%	78.0%	85.8%*
	specific topographies	prevalence among people identified as showing serious or controlled 'other' challenging behaviour	prevalence among adults identified as showing serious or controlled 'other' challenging behaviour	prevalence among children identified as showing serious or controlled 'other' challenging behaviour
	generalised non-compliance	69.2%	54.7%	86.6%***
	temper tantrums	53.7%	48.7%	59.8%
	repetitive pestering	45.8%	42.7%	49.5%
	screaming	30.8%	31.6%	29.9%
	running away	27.6%	18.8%	38.1%**
	overactivity	27.1%	24.8%	29.9%
	other challenging behaviour	22.4%	20.5%	24.7%
	stealing	18.7%	18.8%	18.6%
	inappropriate sexual behaviour	18.7%	23.1%	13.4%
	stripping	7.0%	6.0%	8.2%
	smearing faeces	7.5%	10.3%	4.1%
Note: * indicates difference between child and adults $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$				

Overall, 79% of participants who showed serious or controlled aggression showed two or more forms of specific aggressive behaviours, 19% showed five or more forms. Similarly, 72% of participants who showed serious or controlled self-injury showed two or more self-injurious behaviours, 26% showed five or more forms.

As can be seen there were a small number of differences in the prevalence of general categories and specific forms of challenging behaviours shown by children and adults. With regard to the general categories, more children than adults who were identified as showing challenging behaviour showed destructive and 'other' forms of challenging behaviour. Of the people identified as showing 'serious' or 'controlled' aggression, children were more likely to show meanness or cruelty. Of the people identified as showing 'serious' or 'controlled' other forms of challenging behaviour, children were: more likely to run away and show generalised non-compliance.

A number of specific forms of challenging behaviour occurred more frequently among people identified as showing more demanding challenging behaviour. These were:

- hitting others with objects (overall $\chi^2 = 6.58$, $df = 1$, $p < 0.05$; children $\chi^2 = 5.84$, $df = 1$, $p < 0.05$)
- pulling others hair (adults $\chi^2 = 4.03$, $df = 1$, $p < 0.05$)
- scratching others (overall $\chi^2 = 6.18$, $df = 1$, $p < 0.05$; adults $\chi^2 = 5.03$, $df = 1$, $p < 0.05$)
- hitting own body with hand or other body parts (overall $\chi^2 = 9.04$, $df = 1$, $p < 0.01$; adults $\chi^2 = 11.18$, $df = 1$, $p < 0.001$)
- hitting own body with/against objects (adults $\chi^2 = 4.10$, $df = 1$, $p < 0.05$)
- hitting own head with or against objects (overall $\chi^2 = 5.49$, $df = 1$, $p < 0.05$)
- hitting own head with hand or other body part (overall $\chi^2 = 9.39$, $df = 1$, $p < 0.01$; adults $\chi^2 = 12.29$, $df = 1$, $p < 0.001$)
- teeth grinding (overall $\chi^2 = 3.93$, $df = 1$, $p < 0.05$; adults $\chi^2 = 5.31$, $df = 1$, $p < 0.05$)
- generalised non-compliance (overall $\chi^2 = 7.26$, $df = 1$, $p < 0.01$; children $\chi^2 = 5.67$, $df = 1$, $p < 0.05$)
- overactivity (overall $\chi^2 = 6.72$, $df = 1$, $p < 0.05$)
- running away (children $\chi^2 = 4.74$, $df = 1$, $p < 0.05$)
- screaming (overall $\chi^2 = 5.22$, $df = 1$, $p < 0.05$).

Relationships Between General Forms of Challenging Behaviour

Table 4, below, presents Spearman rank-order correlation coefficients between the four general forms of challenging behaviour in 1988 and 1995.

Table 4: Associations Between General Forms of Challenging Behaviour				
1988		<i>self-injury</i>	<i>destructiveness</i>	<i>other</i>
	aggression	-0.018	0.124**	-0.159***
	self-injury		0.150***	-0.145***
	destructiveness			-0.073
1995		<i>self-injury</i>	<i>destructiveness</i>	<i>other</i>
	aggression	0.173**	0.452***	0.003
	self-injury		0.219***	-0.094
	destructiveness			0.089
Note: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$				

As can be seen, in 1988 people who showed destructive behaviours were more likely to show aggression and/or self-injury, people who showed other forms of challenging behaviour were less likely to show aggression and/or self-injury. In 1995, that pattern of inter-relationships between these general classes of challenging behaviour were somewhat different. While people who showed destructive behaviours were again more likely to show aggression and/or self-injury, presence of 'other' forms of challenging behaviour was unrelated to presence of any other form of challenging behaviour. In addition, people who showed aggression were also more likely to show self-injury.

The Characteristics of the People Identified As Showing Challenging Behaviour

Some of the basic characteristics of the people identified in 1995 in the total population survey undertaken in two localities as showing 'more' and 'less' demanding challenging behaviour are presented in the following sections. Again, for purposes of comparison, the data collected in the 1988 study are also presented.

Gender

In 1995, 68% of the people identified were boys/men. This corresponds closely to the percentage of boys/men (65%) found in the original 1988 survey. Similar percentages of men were found in the 1995 sub-samples of people showing 'more' (69%) and 'less' (65%) challenging behaviour.

Age

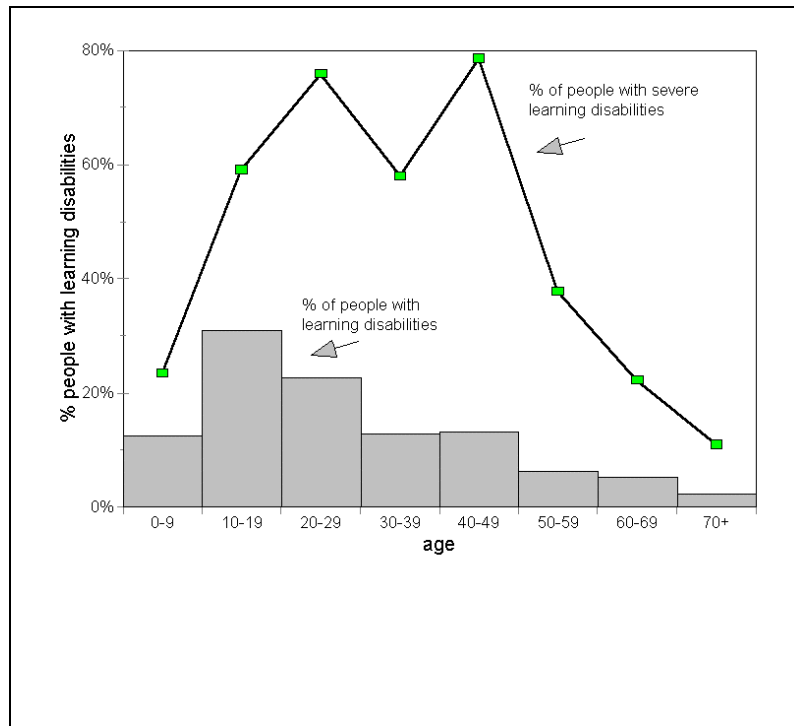
The overall age distribution of people identified in the 1988 and 1995 samples is given in Figure 1. As can be seen, the majority of people identified are young adults. In the 1995 survey, 60% of people were aged between 12 and 35 years of age. Similarly, in the 1988 sample 64% of people identified were between 12 and 35.

In both samples, those people identified as showing 'more' demanding challenging behaviour were significantly younger than those identified as showing 'less' demanding challenging behaviour (for 1995, $t=2.26$, $df=204$, $p<0.05$; for 1988, $t=3.51$, $df=686$, $p<0.001$).

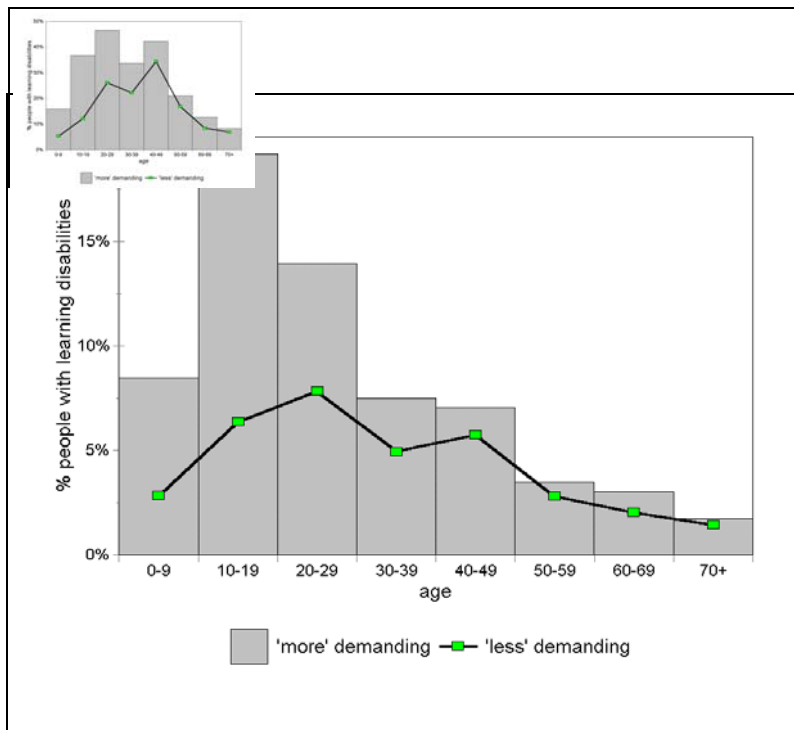
The apparent decline in the prevalence of challenging behaviour at older ages may, of course, simply reflect the relatively young age structure of the overall population of people with learning disability and, in particular, the young age structure of the population of people with *severe* learning disability (who are at greatest risk of showing challenging behaviour). Unfortunately, no reliable information of the overall age structure for the population screened is available for the areas surveyed. It is possible, however, to predict the expected age structure of a population of people with learning disability from other sources.



In Figure 2 we present two age-specific prevalence rates for challenging behaviour based on the predicted age structure of the population screened¹. The first (grey bars) is based on the predicted numbers of people with learning disability within each 10 year age band. The second (line) is based on the predicted numbers of people with severe learning disability within each age band.



As can be seen, both predictions suggest a rise in the prevalence of challenging behaviour during childhood followed by a decline with increasing age. When based on the predicted overall population of people with learning disability, this decline is apparent from school leaving age. When based on the predicted population of people with severe learning disability, this decline in prevalence does not become apparent until age 50.



As noted above, the group of people identified as showing more demanding challenging behaviour was significantly younger than the group showing less demanding challenging behaviour. Figures 3 and 4 present age-specific prevalence rates for people with more and less demanding challenging

behaviour in the combined 1988 and 1995 samples. Prevalence rates are based on the predicted numbers of people with learning disability (Figure 3) and the predicted numbers of people with

¹ Predictions based on data derived from the Sheffield Case Register (Parrott, Emerson, Hatton & Wolstenholme, 1997). Prevalence rates are based on the combined 1988 and 1995 samples.

severe learning disability (Figure 4) in each age band. As can be seen, the decline in age specific prevalence is most noticeable for people showing more demanding challenging behaviour. As age increases during adulthood, the overall severity in the total population of people showing challenging behaviour decreases (ie there are proportionally more people with ‘less’ demanding challenging behaviour in the older age groups).

Residential and Daytime Supports

The current place of residence of participants in 1995 is given below in Table 5.

Table 5: Residential Status of Participants		
	<i>less demanding</i> <i>n = 75</i>	<i>more demanding</i> <i>n = 132</i>
natural or foster family	35%	49%
independent	12%	2%
residential care	53%	49%
$(\chi^2 = 10.3, df = 2, p < 0.01)$		

Of those people in residential care, 79% were living in staffed houses with a small minority 16% resident in hospital. Approximately 50% had been living in their current place of residence for four years or more. Since 1988:

- they had experienced an average of 1.6 moves, ranging from 0 (for 17%) to 15 (1 person);
- 53% had been in hospital;
- 10% had been in a Medium Secure Unit.

Thirty six per cent of the ‘more’ demanding group and 22% of the ‘less’ demanding group were attending primary or secondary school. The percentage of people in various daytime occupations of those **who had left school** are given below in Table 6.

Table 6: Day Services Used by Participants		
	<i>less demanding</i> <i>n = 57</i>	<i>more demanding</i> <i>n = 79</i>
open employment	2%	0%
supported employment	4%	3%
segregated work	9%	3%
FE College	33%	18%
ATC/SEC	55%	51%
None	23%	43%
Note: percentages add up to more than 100 due to people using several different types of service		

Seventy percent of the post-school group received less than 30 hours per week of day services.

The General Health and Social Care Needs of Participants

Table 7, overleaf, presents some basic information on the general health and social needs of children and adults identified as showing more and less demanding challenging behaviour².

Comparisons between the ‘more’ and ‘less’ demanding groups indicated that the ‘more’ demanding group were more likely to:

- ❑ need greater levels of assistance in eating (1988 adults, $\chi^2 = 10.33$, $df = 2$, $p < 0.01$; 1995 adults, $\chi^2 = 9.40$, $df = 2$, $p < 0.01$), dressing (1988 adults, $\chi^2 = 11.93$, $df = 2$, $p < 0.01$; 1995 adults, $\chi^2 = 11.47$, $df = 2$, $p < 0.01$) and washing (1988 adults, $\chi^2 = 18.21$, $df = 2$, $p < 0.001$; 1995 adults, $\chi^2 = 8.01$, $df = 2$, $p < 0.05$)
- ❑ be incontinent (1988 adults, $\chi^2 = 10.67$, $df = 3$, $p < 0.05$; 1995 adults, $\chi^2 = 9.67$, $df = 3$, $p < 0.05$)
- ❑ have more restricted receptive (1988 adults, $\chi^2 = 22.57$, $df = 4$, $p < 0.001$; 1995 adults, $\chi^2 = 11.81$, $df = 4$, $p < 0.05$) and expressive communication (1988 children, $\chi^2 = 6.01$, $df = 2$, $p < 0.05$; 1988 adults, $\chi^2 = 21.76$, $df = 2$, $p < 0.0001$).

Comparisons between children and adults in 1995 indicated that children were:

- ❑ more likely to be independent in dressing ($\chi^2 = 5.05$, $df = 1$, $p = 0.0246$) and be independently mobile (Mann Whitney $z = 2.18$, $p = 0.0294$);
- ❑ less likely to have diagnosis of psychosis ($\chi^2 = 4.63$, $df = 1$, $p = 0.0315$) or non-psychotic mental illness ($\chi^2 = 15.02$, $df = 1$, $p = 0.0001$).

However, comparisons between children and adults in 1988 indicated that children were:

- ❑ less likely to be independent in dressing ($\chi^2 = 18.30$, $df = 1$, $p = 0.0000$), eating ($\chi^2 = 45.02$, $df = 1$, $p = 0.0000$) and washing ($\chi^2 = 8.12$, $df = 1$, $p = 0.0044$), less likely to be continent (Mann Whitney $z = 3.53$, $p = 0.0004$);
- ❑ more likely to have a diagnosis of autism ($\chi^2 = 4.74$, $df = 1$, $p = 0.0294$), visual impairment ($\chi^2 = 8.93$, $df = 1$, $p = 0.0028$), hearing impairment ($\chi^2 = 7.95$, $df = 1$, $p = 0.0048$) and restricted receptive (Mann Whitney $z = 5.63$, $p = 0.0000$) and expressive communication (Mann Whitney $z = 4.12$, $p = 0.0000$).

It seems plausible to suggest that the marked differences between child/adult comparisons in 1988 and 1995 were likely to be due to the extension of the screening procedures in 1995 to include schools for children with mild/moderate learning difficulties (disability).

level of demand >	1995 sample		1988 sample		Combined Sample		
	less n=16	more n=52	less n=37	more n=106	less n=53	more n=158	all n=211
Children							
reported diagnosis of autism	13%	8%	8%	8%	10%	8%	8%
..... psychosis	6%	0%	0%	2%	2%	1%	1%
..... other mental illness	0%	2%	3%	5%	2%	4%	4%
epilepsy	13%	25%	41%	41%	33%	36%	35%
physical disability (restricted mobility)	25%	12%	30%	26%	28%	21%	23%
visual impairment	21%	2%	24%	15%	23%	11%	14%

² Discrepancies in the sample sizes reported in Tables 1 and 7 are due to missing data on the variables of interest.

Table 7: Health and Social Needs of People Identified as Showing Challenging Behaviour							
hearing impairment	0%	4%	9%	8%	6%	7%	7%
dual sensory impairment	0%	0%	0%	3%	0%	2%	2%
incontinent	25%	40%	46%	51%	40%	47%	45%
needs assistance with eating	31%	21%	41%	59%	38%	46%	44%
needs assistance with dressing	63%	58%	65%	82%	64%	74%	72%
needs assistance with washing	50%	59%	70%	86%	64%	77%	74%
restricted expressive communication	19%	29%	65%	79%	51%	63%	60%
restricted receptive communication	63%	62%	86%	93%	79%	83%	82%
Adults	n=59	n=79	n=206	n=339	n=265	n=418	n=683
reported diagnosis of autism	3%	4%	3%	5%	3%	5%	4%
.... psychosis	10%	10%	9%	6%	9%	7%	8%
.... other mental illness	5%	18%	6%	6%	6%	8%	7%
epilepsy	31%	33%	32%	33%	32%	33%	33%
physical disability (restricted mobility)	26%	32%	21%	24%	22%	26%	24%
visual impairment	13%	17%	13%	16%	13%	16%	15%
hearing impairment	13%	6%	4%	8%	6%	8%	7%
dual sensory impairment	2%	1%	1%	3%	1%	3%	2%
incontinent	26%	44%	27%	41%	27%	42%	36%
needs assistance with eating	8%	29%	18%	29%	16%	29%	24%
needs assistance with dressing	35%	64%	49%	64%	46%	64%	57%
needs assistance with washing	51%	72%	59%	76%	57%	75%	68%
restricted expressive communication	29%	46%	44%	63%	41%	60%	52%
restricted receptive communication	56%	66%	64%	78%	62%	76%	70%

The Relationship Between Personal Characteristics and Challenging Behaviour

In this section we will examine the relationships between the personal characteristics and the extent to which the person showed: aggression, destructive behaviour, self-injury, generalised non-compliance, temper tantrums and repetitive pestering. Table 8, overleaf, lists Spearman rank-order correlation coefficients between the extent to which participants showed each form of challenging behaviour and a variety of personal characteristics.

A number of general observations can be made from these data. First, the overall extent to which personal characteristics are associated with the extent to which people are likely to show challenging behaviours varies considerable across different forms of challenging behaviour. Thus, for example, while in 1995 the extent of aggression is not related to any the personal characteristics investigated, self-injury is more common among people with more severe epilepsy, more restricted mobility, more severe hearing impairment, more severe intellectual disability, more severe communication difficulties, reduced self-care skills, greater problems with continence and more stereotypes. Second, the direction of the relationship between specific personal characteristics and challenging behaviour also varies across challenging behaviour. So, for example, while self-injury in 1995 was significantly associated with more severely impaired communication, non-compliance was significantly associated with less severely impaired communication.

Multivariate statistical analyses were also undertaken to identify which personal characteristics acted as key predictors of whether a person is likely to show aggression, destructive behaviour, self-injury and the three most common forms of ‘other’ challenging behaviour: generalised non-compliance, temper tantrums and repetitive pestering. Again, these analyses were undertaken separately for the 1988 and 1995 samples. Again, a person was deemed to show that general form of challenging behaviour if informants rated it as constituting a ‘serious’ or ‘controlled’ management problem. ‘Controlled’ refers to behaviours which informants rated as likely to cause a serious management problem were it not controlled by the use of specific preventative measures (e.g. avoidance of particular activities, use of strengthened glass). The analysis was undertaken on a sub-set of 245 people in 1995 and 679 people in 1988 for whom complete information was available on all independent and dependent variables of interest. These analyses employed a logistic regression model in which independent variables (personal characteristics) were entered in a stepwise manner conditional on them significantly increasing the predictive power of the regression equation. The results of these analyses are presented below in Table 9.

1988						
<i>personal characteristic</i>	AGG	SI	DEST	NON-C	TT	RP
age	.008	-.092*	-.093*	.085	.002	.012
gender (male)	-.020	-.052	.055	.008	-.106*	.034
severity of epilepsy	-.043	-.134***	-.049	.037	-.007	.018
mobility	.056	-.248***	.048	.055	-.045	.148***
visual impairment	.103**	-.061	.027	.050	-.000	.079
hearing impairment	.071	-.032	-.005	-.014	.032	.089*
self-care skills	.117**	-.311***	-.001	-.074	.129**	.185***

continence	.116**	-.215***	.034	-.002	.074	.213***
general communication skills	.122**	-.277***	-.052	.009	.086	.279***
expressive communication	.105**	-.271***	-.026	-.003	.103*	.291***
reported diagnosis of .. autism	.038	.001	-.060	-.096*	-.021	.101*
.. psychosis	.048	-.007	.033	.056	.027	.074
.. other mental illness	-.020	.042	-.016	.095*	.021	.101*
stereotypy	.074	-.266***	-.014	-.025	.046	.059
1995						
<i>personal characteristic</i>	AGG	SI	DEST	NON-C	TT	RP
age	-.058	.024	-.008	-.300***	-.021	-.041
gender (male)	.004	-.062	.127*	-.054	-.105	.117
severity of epilepsy	.022	-.210**	-.001	.017	.115	.012
mobility	.038	-.214**	.031	.138*	-.009	.105
visual impairment	.108	-.102	.011	.136	.068	.098
hearing impairment	.008	-.141*	-.127*	.024	.095	.027
intellectual ability	.061	-.338***	-.063	.122	.123	.132
self-care skills	.058	-.364***	-.027	.084	.136	.103
continence	.005	-.270***	.010	.053	.104	.160*
general communication skills	.040	-.400***	-.092	.161*	.130	.212**
expressive communication	.119	-.330***	.028	.210**	.215**	.240***
reported diagnosis of .. autism	.019	-.044	.054	-.047	.027	.047
.. psychosis	.001	.075	-.028	-.160*	-.041	-.037
.. other mental illness	.117	.017	.093	-.132	.019	-.027
stereotypy	.056	.475***	.146*	-.083	-.135	.001
Notes:	1	a higher score on measures of challenging behaviour denotes more serious challenging behaviour, a higher score on other variables indicates either the absence of the characteristic (eg autism) or greater levels of ability. As such, positive correlations indicate that people with greater levels of ability (absence of disability) show more severe challenging behaviour, negative correlations indicate that people with lower levels of ability (presence of disability) show more severe challenging behaviour.				
	2	* p < 0.05, ** p < 0.01, *** p < 0.001				
	3	AGG = aggression, SI = self-injury, DEST = destructive behaviours, NON-C = generalised non-compliance, TT = temper tantrums, RP = repetitive pestering				

Table 9: Summary Results of Logistic Regression Analyses Undertaken to Identify Variables Predictive of Presence of Different Forms of Challenging Behaviour			
<i>dependant variable (challenging behaviour)</i>	<i>% correct classification</i>	<i>related independent variables (personal characteristics)</i>	<i>significance</i>
1988			
aggression	59%	(greater) self-care skills (less severe) epilepsy	p < 0.01 p < 0.05
self-injury	75%	(more restricted) mobility (poorer) general communication skills (more) stereotypies	p < 0.001 p < 0.01 p < 0.01
destructive behaviour	70%	(younger) age	p < 0.01
non-compliance	55%	(diagnosis of) autism	p < 0.01

Table 9: Summary Results of Logistic Regression Analyses Undertaken to Identify Variables Predictive of Presence of Different Forms of Challenging Behaviour			
temper tantrums	60%	(greater) self-care skills (less restricted) mobility (female) gender	p < 0.001 p < 0.001 p < 0.01
repetitive pestering	73%	(greater) communication skills (less restricted) mobility	p < 0.0001 p < 0.05
1995			
aggression	64%	(greater) expressive communication	p < 0.01
self-injury	76%	(fewer) self-care skills	p < 0.001
destructive behaviour		no significant predictors	
non-compliance	89%	(no) psychotic mental illness	p < 0.05
temper tantrums	76%	(greater) expressive communication (female) gender	p < 0.05 p < 0.05
repetitive pestering	67%	(greater) expressive communication (less restricted) mobility	p < 0.01 p < 0.05

As can be seen, there are a number of general consistencies between the analyses undertaken on the 1988 and 1995 samples. These include:

- aggression being more likely to be shown by less severely disabled people (greater self-care skills and less severe epilepsy in 1988, greater communication skills in 1995);
- self-injury being more likely to be shown by more severely disabled people (more restricted mobility and communication skills in 1988, fewer self-care skills in 1995);
- temper tantrums being more likely to be shown by less severely disabled people (greater self-care skills and less restricted mobility in 1988, greater expressive communication in 1995) and by girls/women;
- repetitive pestering being more likely to be shown by less severely disabled people (greater communication skills and less restricted mobility in both 1988 and 1995).

Summary & Discussion

In this report we have presented information from a total population survey of challenging behaviour shown by people with learning disability undertaken in two localities in the North-West of England. We have also presented re-analyses of data collected by the Hester Adrian Research Centre in seven localities in the North-West of England in 1988 (Kiernan & Qureshi, 1993; Qureshi, 1994; Qureshi & Alborz, 1992).

As with all surveys, the data and analyses do need to be treated with a certain amount of caution. The majority of the data was collected from key informants (keyworkers, teachers) and, as such, is limited by their knowledge of the person's abilities, situation and behaviour. While we made strenuous attempts to ensure that informants had a good knowledge of the person and their situation, some inaccuracies in the data are inevitable.

It is also important to treat the results of the logistic regression analyses with some caution. Such analyses are, of course, correlational. They can never provide unequivocal evidence of causality. In addition, missing or incomplete data significantly reduced the sample size available for the regression analyses. Consequently, the results are perhaps more useful for exemplifying broad themes, than for detailed analyses of predictors of specific behaviours.

To summarise, the main results (broadly consistent with previous research) suggest that:

- ❑ challenging behaviours are shown by 10-15% of people with learning disability who are in contact with educational, health or social care services for people with learning disability (64% of people identified showed 'more demanding' challenging behaviour);
- ❑ the most common forms of challenging behaviours which created serious problems of management for carers (or would do were it not for specific controlling measures currently implemented in the setting) were 'other' forms of challenging behaviour³ (shown by 9%-12% of all people screened in 1988 and 1995), aggression (7%), destructive behaviour (4%-5%) and self-injury (4%);
- ❑ in both 1988 and 1995 the majority of people identified as showing challenging behaviour showed two or more of these four general forms of challenging behaviour;
- ❑ people who showed 'more demanding' challenging behaviour were more likely to hit others with objects, pull others' hair, scratch others, hit their own body with their hand or other body parts, hit their own body with or against objects; hit their own head with or against objects, hit their own head with their hand or other body part, grind their teeth, show generalised non-compliance, be overactive, run away and show repetitive screaming;
- ❑ approximately two-thirds of the people identified were boys/men;
- ❑ close to two-thirds of the people identified were adolescents or young adults;
- ❑ approximately 50% of the people identified as showing more demanding challenging behaviour were living with their families;
- ❑ over one-third of the adults identified as showing more demanding challenging behaviour had no day service;
- ❑ the people identified were reported to have a wide range of additional health and social care needs. People who showed 'more demanding' challenging behaviour were more likely to need greater levels of assistance in eating, dressing and

³ Most commonly, generalised non-compliance, 'temper tantrums', repetitive 'pestering', screaming and running away.

- washing, be incontinent and have more restricted expressive and receptive communication;
- among the people identified as showing challenging behaviour, aggression, ‘temper tantrums’ and repetitive pestering were more likely to be shown by people with less severe disability, and self-injury was more likely to be shown by people with more severe disability.

Some of the more important implications of these results for policy and practice will be briefly outlined below.

Implications for Workforce Planning and Training

As noted above, the data from 1988 and 1995 suggest that challenging behaviours are shown by approximately 10-15% of children and adults with being supported by educational, health or social care services for people with learning disability. Sixty four per cent of people identified showed ‘more demanding’ challenging behaviour. If we assume an administrative prevalence for learning disability of 0.45%, this suggests that, within a ‘hypothetical’ general population of 500,000 people there will be:

- 2,250 people with learning disability
- of whom 225-340 will at any one time show challenging behaviour,
- including 110-225 people who will be showing ‘more demanding’ challenging behaviour.

These data clearly reinforce current guidance from the Department of Health (Department of Health, 1993) which presents a strong case to suggest that meeting the health and social care needs of people with challenging behaviour must be a central concern of *mainstream* services for people with learning disability. A similar argument has recently been made regarding services for children with learning disability and challenging behaviour (Mental Health Foundation, 1997).

Such an approach does, of course, have significant implications regarding the competencies expected of people employed within mainstream services and the competences of specialised staff acting in a consultative role to such services. At present, however, increasing concern is being expressed regarding the apparent loss of generic learning disability expertise as a result of abandonment of the training of specialised teachers in learning disability and more recent changes in the training of nurses and social workers (Mental Health Foundation, 1996, 1997). In addition, few opportunities for specialised training in supporting people with challenging behaviour currently exist (cf McGill & Bliss, 1993).

As a result, we would support the recommendation of the Mental Health Foundation (1996) that the Department of Health undertake a major review of the future staffing and training needs for learning disability services and that: (1) Regional Offices of the NHSE review current arrangements for commissioning training to ensure that future health professionals will have the competencies required to support people with learning disability and challenging behaviour; and (2) Health and Local Authorities review the arrangements for training and development of staff among local providers.

Implications for the Organisation of Specialist Services

The relatively high prevalence of challenging behaviour, when combined with the great diversity and complexity of the group of behaviours subsumed by the term challenging behaviour, presents a number of challenges for the organisation of specialised support services. These include:

- ensuring that specialised support is available to (the relatively large number of) people in need;
- ensuring that forms of support are appropriate to the diverse situations and circumstances of people with challenging behaviour and their families;
- ensuring that specialised support has access to specific skills and knowledge appropriate to the range of challenging behaviours shown by people with learning disability.

Evidence from other components of the project (Kiernan et al 1997a; Emerson et al, 1997) and elsewhere (e.g. Emerson et al, 1996; Lowe et al, 1996) indicate that current problems may exist within each of these three areas.

We recommend that Health and Local Authorities jointly review the arrangements for providing specialised support to people with challenging behaviour among local providers on these three dimensions. Such a review is likely to raise issues regarding:

- the volume of current provision;
- the development of eligibility and targeting criteria for specialised support services;
- arrangements for caseload management and throughput;
- the viability of single-model approaches (e.g. specialist support only being available through admission to an in-patient NHS unit, or specialist support only being available through a peripatetic community support team);
- arrangements for the co-ordination of services for people with challenging behaviour;
- the development of a comprehensive strategy for services for people with challenging behaviour (cf Mansell et al, 1994);
- issues of coverage and equity of access (cf Emerson et al, 1997);
- arrangements for pooling resources and expertise across agency boundaries and the viability of comprehensive local specialist services.

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