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## **Service use and access in young children with an intellectual disability or global developmental delay: associations with challenging behavior**

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**Title:** Service use and access in young children with an intellectual disability or global developmental delay: associations with challenging behaviour

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**Running head:** Service use in children with an intellectual disability

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### **Abstract**

*Background* Challenging behaviours are frequently shown by children with an intellectual disability. This study documents service use within this population and explores its relationship with challenging behaviours and child and parent characteristics.

*Method* Forty-nine mothers of young children with an intellectual disability or global developmental delay completed questionnaires focusing on child behaviour, parental mental health, and service use.

*Results* Maternal mental health was not associated with services accessed. Cost of services accessed differed by topography of challenging behaviour for destruction of the environment or aggression. No differences were noted for self-injurious behaviour.

*Conclusion* In this small study, topography of challenging behaviour impacts on the frequency and/or duration (and therefore cost) of community-based healthcare accessed. Behaviours that have external impact, such as aggression and destruction of the environment are associated with a higher cost of services used, a pattern not noted for behaviours that had less external impact (e.g., self-injurious behaviour).

**Key Words:** intellectual disability; challenging behaviour; behaviour problems; service use

## Service use and access in young children with an intellectual disability or global developmental delay: associations with challenging behaviour

### **Introduction**

Challenging behaviours, such as self-injury and aggression, are shown by approximately 10-20% of individuals with an intellectual disability (ID) and require a disproportionate amount of resources (Davies & Oliver, 2013; Mansell, 1992). Psychology, psychiatry, and dietetics are frequently accessed (Knapp, Comas-Herrera, Astin, Beecham, & Pendaries., 2005), all of which are services which are overburdened and have significant waiting times.

The majority of individuals show more than one form of challenging behaviour (e.g., self-injury and aggression (Emerson et al., 2001) and these behaviours persist over many years (Taylor, Oliver, & Murphy, 2011; Totsika & Hastings, 2009). They significantly impinge on the quality of life of people with severe ID and their families and can lead to exclusion and the need for costly residential and specialised services (Hastings, 2002; Schwartz & Rabinovitz, 2003). Challenging behaviour is associated with increased maternal stress and reduced psychological well-being, even in parents of children under five (Totsika, Hastings, Emerson, Berridge, & Lancaster, 2011; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011).

There is a paucity of research focusing on the economic costs associated with ID (Doran et al., 2012) ) and global developmental delay (GDD), limiting the extent to which such evidence can be used to inform or guide policy on intervention (Romeo & Molosankwe, 2010). The available studies on different aspects of costs associated with challenging behaviour in individuals with ID have focussed predominantly upon adults. Studies using both large scale surveys and detailed analyses of case studies have all reported that level of perceived need (Hassiotis et al., 2008), level of ability, and challenging behaviour (Knapp et

al., 2005; Strydom et al., 2010) are associated with higher health and social care costs in adults with ID. Toms, Totsika, Hastings, and Healy (2015) note that children with ID are more likely to access primary, educational/social, and specialist mental health services than children without ID. The overall level of access to services was low in their sample, suggesting potentially high levels of unmet need. Studies focusing on the cost of autism or autism spectrum disorder (ASD) within the UK have also reported that lower adaptive ability (but not lower IQ) is associated with higher healthcare costs in adolescents aged 14-17 (Barrett et al., 2014) and that a dual diagnosis of autism spectrum disorder and ID is associated with higher health, social, and educational costs than a diagnosis of an ASD alone (Buescher, Cidav, Knapp, & Mandell, 2014).

Curtis (2013) reports that the average cost of care for children living with any disability is estimated at £171 a week for children supported by families and £696 per week for “looked after” children (i.e., children within the care system). To date, such data are not available for healthcare costs for young children with ID (Romeo & Molosankwe, 2010), with or without challenging behaviour. Einfeld et al.’s (2010) Australian study recruited 109 parents of individuals with ID, ranging from 1 to 38 years ( $\bar{x} = 13.34$ ). They used the Client Service Receipt Inventory (CSRI) to record both out-of-pocket expenses for families (e.g., to replace broken items) and opportunity costs (cost of family time spent caring for each child) for each family that are above the cost of raising a child without ID. They note that the total additional cost for caring for a child with ID was AUS\$1983 per week (in 2008-2009). Within this sample, higher scores on the Developmental Behaviour Checklist (used to measure behavioural and emotional problems) were associated with increases in both opportunity costs and total costs”.

Barron, Molosankwe, Romeo and Hassiotis (2013) also used the CSRI to look at health, education, and social services accessed in 27 young people (aged 16-18) with ID and

challenging behaviour transitioning between child and adult services in one London borough. They report the average weekly hospital cost as £10.97 ( $s = £50.47$ ) and the average weekly community healthcare cost (including home help and home care worker) as £221.14 per week ( $s = £452.77$ ). Severity of ID (mild, moderate, severe), but not severity of challenging behaviour, was associated with higher costs for health services. However, as the sample only included individuals showing challenging behaviour, it was not possible to compare the relationship between the presence of these behaviours and the costs of services accessed.

The importance of considering the form of challenging behaviour in research studies has been demonstrated in a number of ways. Meta-analyses have identified different risk markers for self-injury, aggression, and destruction of the environment (McClintock, Hall, & Oliver, 2003), some of which differ with age (Petty & Oliver, 2005). Prevalence rates for self-injury and aggression differ with aetiology of ID (Arron, Oliver, Moss, Berg, & Burbidge, 2011) and specific forms of challenging behaviour are associated with increased prevalence of some conditions or health problems (e.g., self-injurious behaviour and pain (Bosch, Van Dyke, Smith, & Poulton, 1997). Despite this, it is not known whether specific forms of challenging behaviours are associated with access to different numbers or types of services. Given the suggestion that behavioural excesses (increases in behaviour e.g., shouting, aggression) have a greater impact upon carers than behavioural deficits (reductions in behaviour e.g., apathy), and that such behavioural excesses are more common in adults with Down syndrome referred to clinical services than those not referred to clinical services (Adams et al., 2008), it seems reasonable to assume that different challenging behaviours will also have differing impacts upon carer behaviour. Therefore, in this study, we seek to generate data on healthcare costs for children showing the three main topographies of challenging behaviour; aggression, destruction of the environment, and self-injurious behaviour.

The key aims for this paper were to firstly describe the range and cost of services accessed by children with ID and GDD. The degree to which services accessed and their associated costs are associated with child characteristics including age, form, and severity of challenging behaviour and degree of ID or GDD will then be explored. Finally this paper aims to explore the degree to which services accessed and their associated costs are associated with parental anxiety and depression.

## **Method**

### ***Research design***

A cross-sectional design was used to collect data from a community-based sample. A combination of questionnaire and interview measures was administered to all participants and analysed using SPSS Version 20.

### ***Ethical approval***

Ethical approval was received from the University of Birmingham Research Ethics Committee. As the research was undertaken in an NHS setting, ethical approval was also obtained from the Integrated Research Applications System (IRAS) Ethical Committee, which is a UK-wide system provided on behalf of the Health Research Authority. Permission was also obtained from the appropriate Local Research Network (on behalf of the NHS Healthcare Trust).

### ***Participants***

Parents who identified their children as having a diagnosis of ID or a GDD were recruited while waiting for appointments at Child Development Centres in a large UK city. GDD is a diagnostic term usually reserved for younger children (typically under 5 years of age) who have significant delays in two or more developmental domains. A diagnosis of GDD is predictive of a future diagnosis of an ID (Accardo & Capute, 1995).



Parents were given as much time as required to read the information sheet and complete the written consent form before being given the questionnaire pack. Following completion of the initial questionnaire pack within the Child Development Centre, parents were later asked to complete a telephone interview.

This resulted in a sample of 49 parents of children aged 2 to 9 years ( $\bar{x} = 6.67$ ,  $s = 2.7$ ). Demographic information is summarised in Table 1. Thirty-seven (75.5%) of the children were male. Sixty-seven percent of the participants identified themselves as being from a White British or White other background, 12.5% from a mixed background, 14.5% from a south Asian background, and 4% of Black Afro-Caribbean origin. Thirty-six (73.5%) of the parents stated that their child had a diagnosis of ID and the remainder (26.5%) stated that their child had a diagnosis of GDD. This was corroborated by the ability standard scores on the Vineland Adaptive Behavior Scales Daily Living Skills domain which ranged between 23 and 77 ( $\bar{x} = 63.8$ ,  $s = 9.9$ ). All children lived at home with their biological parents. Twelve children (24.5%) had a diagnosis of an ASD and a further seven (14.3%) had been told by a professional that their child had “autistic traits” (as reported by the parents).

+++ Insert Table 1 about here+++

### ***Measures***

*Self-injury, Aggression and Destruction Screening Questionnaire (SAD-SQ: Davies & Oliver, 2016).* The SAD-SQ is a 30-item screening questionnaire designed to assess a child's risk of developing self-injurious, aggressive, or destructive behaviour. It includes items used to assess the presence of putative risk markers for challenging behaviour; genetic syndrome, ID, health difficulties, possible ASD, repetitive/restrictive behaviour, and overactivity/impulsivity. It also includes items to assess current aggressive, destructive, and self-injurious behaviour in terms of presence (Yes/No), severity (two items rated on 5-point scale), frequency (one item rated on 5-point scale), and level of concern (on a 5-point scale). These items can be summed to achieve a total severity score for each form of challenging behaviour, Davies and Oliver (2016) report good reliability, as well as concurrent and convergent validity of the SAD-SQ.

*The Vineland Adaptive Behavior Scale – Survey Form (VABS II; Sparrow, Balla, & Cicchetti, 2005).* Adaptive behaviour was assessed using the Vineland Adaptive Behavior Scales -II (VABS, Survey form; Sparrow et al., 2005). Although all children had a diagnosis of ID or GDD, standard scores on the daily living skills subscale were used as a validation of this diagnosis as well as an estimate of level of adaptive ability (as per Adams, Horsler, & Oliver, 2011).

*Client Service Receipt Inventory for children with Intellectual Disabilities (CSRI-CID)* The CSRI enables estimation of component and total costs of service provision for an individual child. It is a validated tool to measure service use and family inputs and has been used in a range of studies to assess the cost of providing services to people with ID both inside and outside of the United Kingdom (Einfeld et al., 2010; Hassiotis et al., 2008; Jarbrink, Fombonne, & Knapp, 2003; Romeo, Knapp, Morrison, et al., 2009; Romeo, Knapp, Tyrer, Crawford, & Oliver-Africano, 2009; Strydom et al., 2010).

The CSRI for children with Intellectual Disabilities (CSRI-CID), adapted from Beecham & Knapp, 2001) was used to collect details on health care services accessed in the previous six months. It records items such as contacts with hospital or community based professions, other health services, and any outpatient or inpatient attendances. The CSRI-CID details inpatient stays (and which department), outpatient hospital appointments (with 13 different professions listed and space for listing any other professions), and community based appointments (with 21 different professions listed and space for listing any not mentioned). As this study focussed upon healthcare costs, data were not collected for unpaid carer hours or educational services. This measure was conducted as a telephone interview to ensure the parents or carers could ask for any clarification on the professions listed.

Direct costs of healthcare appointments were calculated for each child and derived by combining the healthcare appointment and services accessed data with unit cost data. Unit costs were taken from published documents (Curtis, 2013) and reflected both frequency and duration of appointments. Where these were not available, specific costings were identified through individual papers (Henderseon et al., 2013). Costs were calculated for community based services, hospital based services (inpatient and outpatient services) and total services (combined hospital and community based services). As the data were collected in 2013 and cost figures were taken from 2013, the costs were not corrected for inflation within this study.

*Hospital Anxiety and Depression Scales (HADS; Zigmond & Snaith, 1983).* The HADS was used to assess parental anxiety and depression. Each item is scored on a 4-point Likert scale from 0-3, resulting in a maximum possible score of 21 for each subscale. Good test-retest reliability and concurrent validity are reported at subscale and total score levels including for parents of children with a neurodevelopmental disability (Bjelland, Dahl, Haug, & Neckelmann, 2002; Jones, Hastings, Totsika, Keane, & Rhule, 2014).

## ***Analyses***

All analyses were performed using the Statistical Package for the Social Sciences (SPSS) version 20. Descriptive statistics were used to summarise sample data. Parametric tests (*t*-test) were used for normally distributed continuous data and bootstrapped *t*-tests (based on 1000 cases) were used for skewed continuous data (such as costs data) as per Knapp et al. (2005). All correlations were Spearman's Rho as costs data are typically not normally distributed. Non-parametric statistics (Mann-Whitney) were used for comparisons between non-continuous data. Chi-squared tests were used to compare dichotomous data where appropriate. The association between levels of need and costs was explored with Spearman's correlation statistics.

## **Results**

### ***Description of challenging behaviour***

Forty-one (83.7%) out of the 49 children were reported to show aggression, 31 (63.3%) were showing destruction of the environment and 23 (46.9%) were showing self-injurious behaviour. Almost all (96.8%) of the children showing destruction also showed aggression. There were no differences in age or VABS daily living skills standard score (used as an estimate of ability) between children who did and did not show aggression (age:  $t(47) = 1.53$ ,  $p = .13$ ; VABS DLS:  $t(47) = -.37$ ,  $p = .71$ ), destruction of the environment (age:  $t(47) = 1.30$ ,  $p = .20$ , VABS DLS:  $t(47) = .16$ ,  $p = .16$ ), or self-injurious behaviour (age:  $t(47) = .16$ ,  $p = .88$ , VABS DLS:  $t(47) = .12$ ,  $p = .90$ ).

Five children (10.2%) did not show any challenging behaviour, 10 (20.4%) showed only one challenging behaviour, seventeen (34.7%) showed two types of challenging behaviour and seventeen (34.7%) showed all three types of challenging behaviour.

### ***Pattern of service use***

The number of different healthcare professions seen by each child in the previous six months ranged from 1 to 27 ( $\bar{x} = 5.33$ ,  $s = 4.48$ ). The average number of professions seen within a hospital setting (inpatient or outpatient) was 1 (range 0-11,  $s = 1.86$ ) and 4.32 professions in a community setting (range 1-16,  $s = 3.02$ ). The three professions that children had most commonly seen in the last six months were community paediatrician ( $n = 36$ ), general practitioner ( $n = 18$ ), and dentist ( $n = 16$ ).

The cost for hospital and community appointments in the last six months ranged from £46.33 to £1699.55 ( $\bar{x} = £451.65$ ,  $s = £414.49$ ). The average direct costs of hospital appointments were £89.49 ( $s = £208.35$ , range £0-£1160) and for community based appointments the average direct costs were £362.16 ( $s = 328.95$ , range £34.50-£1282.33). The three professions with the highest cost appointments across all participants across the six months duration were community paediatricians (total cost across all children £5716.38), general practitioners (£3317.40), and Speech and Language Therapists (£2834.00).

#### ***Association between service use and child characteristics***

Correlations and *t*-tests (with bootstrapping where applicable) were performed to examine any association between challenging behaviour and services accessed, and to determine if child, parent, or demographic variables (e.g., age, gender, ethnicity, VABS daily living standardised score) were associated with services accessed.

The correlations are summarised in Table 2. After correcting the alpha value to .01 to correct for the number of correlations undertaken, there were no significant relationships between the number of different professions seen or the cost of appointments in the community, at hospital, or combined and child age, ability, overactivity, impulsivity, number of challenging behaviours, or health problems.

+++ Insert Table 2 about here +++

Summarised in Table 3, bootstrapped *t*-tests (adjusted where appropriate for unequal variances) did not identify any significant difference between males and females on the number or cost of combined, hospital, or community professions seen. There was also no difference between children from white and other ethnic backgrounds or those with or without a diagnosis of autism (as per parent report) or autistic traits on the number or cost of combined, hospital, or community professions seen.

+++ Insert Table 3 about here +++

To further explore the relationship between challenging behaviour and professions seen, comparisons were made between those who were and who were not showing the three most common forms of challenging behaviour; self-injury, aggression and destruction of the environment. The data are summarised in Table 4. Preliminary tests for the equality of variances indicates that the variances of the two groups were significantly different for the cost of community appointments and total cost of appointments between those who do and do not show aggression ( $F = 7.74, p = .008$ ;  $F = 5.43, p = .024$ ) and those who do and do not show destruction ( $F = 8.63, p = .005$ ;  $F = 14.41, p < .001$ ). Therefore, where appropriate, bootstrapped *t*-tests were performed that do not assume equal variances.

++ Insert Table 4 about here +++

No significant differences were found between children who did and did not show self-injury in terms of the number of community based or hospital based professions seen, or

in the cost of these appointments. The Cohen *d* effect sizes (based on Dunst & Hamby, 2012) for these comparisons were small to insignificant ( $d < .49$ ).

There was no significant difference between the number of different professions seen in hospital and/or the community between children who do and do not show aggression. However, the costs of the appointments with community professionals in the last six months were higher for children who were showing aggression ( $t(46.9) = -4.09, p < .001, d = .75$ ) suggesting they are accessing longer and/or more frequent appointments than children who do not show aggression. This pattern was consequently noted for the combined hospital and community appointments costs ( $t(29.6) = -2.90, p = .007, d = .64$ ). The Cohen's *d* effect size for the cost of both the community appointments and the combined community and hospital appointments were medium (see Table 4).

Given that 30 out of the 31 children showing destruction were also showing aggression, it is unsurprising that the same pattern was also noted for destruction of the environment. Although the number of professions seen did not differ between children who did and did not show destruction of the environment, the costs for the appointments in the last six months for children who do show this behaviour are significantly higher for their appointments with community professionals ( $t(45.61) = -2.62, p = .01, d = .67$ ) and combined hospital and community appointments ( $t(43.74) = -2.92, p = .006, d = .71$ ). As shown in Table 4, the Cohen's *d* effect size for the costs of both the community appointments and the combined community and hospital appointments were medium.

Correlations between the severity score and the service use data did not identify any significant associations between severity of aggression, destruction of the environment, or self-injurious behaviour and number or cost of professions seen in the community, or when combined (see Table 2).

A one-way Analysis of Variance was undertaken to compare the number of professions and cost of healthcare appointments between those displaying no, one form, two forms and three forms of challenging behaviour. There were no significant differences between children showing different numbers of challenging behaviours and the number of professions seen in the community, hospital, or combined. Summarised in Table 4, there was no significant difference between children showing no, one, two, or three forms of challenging behaviour in the cost of hospital appointments or combined appointments, but there was a significant difference and medium effect size in the cost of community appointments ( $F(3,45) = 3.0, p = .04, d = .63$ ). LSD post-hoc comparisons identified that the difference is between those showing one and three types of challenging behaviour ( $p = .01$ ).

#### ***Association between service use and parental mental health***

The association between service use and parental mental health was explored by correlating the anxiety and depression subscale raw scores with the number of different professions seen in the community, at hospital, or combined and their associated costs. Neither parental anxiety nor depression were significantly correlated with any of the healthcare appointment variables (see Table 2).

#### **Discussion**

The aim of this study was to explore the relationship between child and parent variables and the number or the cost of health services accessed by children with ID or GDD as reported on the CSRI parent interview.

The results highlight specific factors that are associated with elevated costs of community based health services accessed. Whilst the sample is small, medium effect sizes are reported for all the significant results. When examined in more detail, the results show that children displaying destruction of the environment or aggression accessed community



based healthcare services that cost 1.9 and 2.5 times (respectively) more than services accessed by children who do not show these behaviours. There was no significant difference in the cost of services accessed between children who do and do not show self-injurious behaviour. There were no relationships between parental mental health scores on the HADS and healthcare professions seen or their associated costs.

It could be proposed that these results support previous conclusions (e.g. Strydom et al., 2010) that service use in adults with ID was, in part, related to needs. Whilst this could be suggested for the children with aggression and destruction of the environment who are accessing more services (in frequency or intensity, not range) than children not showing these behaviours, it is not the case for children who are showing self-injury.

The finding that challenging behaviour is associated with higher out-of-pocket expenses is one that has been demonstrated across a wide age range of individuals with ID (Einfeld et al., 2010). Similar findings have been reported in adults with ID with regard to both social care costs, such as out of area placements (Allen, Lowe, Moore, & Brophy, 2007), and healthcare costs, for example, increased appointments with psychologists, psychiatrists, dentists (Knapp et al., 2005). This study is the first, to our knowledge, to explore these healthcare costs within a young child population, and to explore the impact of form of challenging behaviour as well the association with parental levels of depression and anxiety on healthcare costs specifically.

Within this small sample, children aged 9 and under who are showing aggression and destruction of the environment are accessing community-based healthcare services that cost at least twice as much as children who are not showing these behaviours. This highlights the need for access to effective intervention for challenging behaviour within this population. Aside from accessing more healthcare services, children displaying challenging behaviour are at an increased risk of a range of negative outcomes, including social exclusion, physical

harm, abuse, an exposure to ineffective interventions and a failure to access evidence-based interventions (Cooper et al., 2014). The behaviours also have an impact upon the mental and physical health of carers, with studies reporting increased physical injuries, increased financial burdens and a reduced quality of life (Davis & Gavidia-Payne, 2009).

There are a number of limitations to this study. The sample size is small and consequently the analyses may be underpowered to identify the impact of additional variables (e.g., level of ID) on service use that have previously been reported in adult samples. Larger samples would allow exploration of possible non-linear relations and the role of moderating or mediating variables and a control group of typically developing children would have allowed for a clearer benchmarking of costs. However, even in studies with larger samples, results only explain a third of the observed variance in costs (Strdom et al., 2010), highlighting the complexity of the data. There is therefore a clear need for multi-site replications of this study in the future which includes a broader range of individual, location and environmental factors, collecting data on unpaid carer hours and non-healthcare services accessed.

As a result of the small, community-based sample within one county, the results may not be generalizable to the whole population of families of children with ID or GDD. The figures are higher than those reported previously (Barron et al., 2013) for London based healthcare costs, but this may be due to an increased input of healthcare appointments in the early years, around the time of diagnosis and educational planning. It may be that the parents of children with fewer healthcare appointments or less significant behavioural problems were the only ones who were able to commit to completing the telephone interview. There may also be specific groups of children, such as those with rare genetic syndromes (of which there were none identified in this study), that may have a different pattern of healthcare service use due to specific healthcare needs.

Relying on parental recall of healthcare appointments over the past six months (especially duration of appointment) introduces an obvious threat to the construct validity of the data collected. However, any difficulties in recall or recall bias would be expected to be equally distributed throughout the groups, and so would not explain the significant differences noted for two out of the three topographies of challenging behaviour. A comparison of cost data collected using medical notes and the CSRI reports a strong correlation (0.76) (Patel et al., 2005). However, they suggest that medical records do not always detail duration of appointments, limiting the extent to which costs can be accurately calculated. Other authors have calculated costs from services documented or by accessing information on fees paid for residential care (Hassiotis et al., 2008). American studies have also used medical claims databases to produce healthcare cost estimates for children with a neurodevelopmental disability (Leslie & Martin, 2007), although this has its own limitations with regard to non-healthcare related costs.

In summary, this is the first study exploring the associations between topographies of challenging behaviour in young children with ID or GDD and healthcare services accessed. Even within this small sample of children aged 9 and under, the impact of challenging behaviour on services accessed is notable, with those showing aggression and destruction of the environment accessing community-based healthcare services that cost at least 1.9 times as much as children who are not showing these behaviours. This highlights the need for effective and accessible early intervention services for these children.

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**Table 1:** Demographic Information for the Total Sample and Subsamples by Topography of Challenging Behaviour.

		<i>n</i>	Mean Age	% Male	% ASD	Ethnicity % white
Total sample		49	6.7	75.5	25.4	67.0
Aggression	Present	41	6.4	78.0	41.5	73.1
	Absent	8	8.0	62.5	25	37.5
Destruction of environment	Present	31	6.3	71.0	45.2	67.7
	Absent	18	7.3	83.3	27.8	66.6
Self-injurious behaviour	Present	33	6.6	69.6	43.5	69.5
	Absent	26	6.7	80.8	34.6	64.8
	None	5	8.4	80	20	20
Forms of challenging behaviour	One	10	7.5	70	40	90
	Two	17	5.6	88.2	29.4	64.7
	Three	17	6.8	64.7	52.9	70.6

**Table 2:** Spearman's Rho Correlational Coefficients for Child and Parental Variables to Professions Seen and Direct Costs.

	Number of professions			Cost of healthcare appointments		
	Community	Hospital	Combined	Community	Hospital	Combined
Age	-.19	-.15	-.20	-.21	-.20	-.22
Vineland Adaptive Behavior Scales Daily Living Skills standard score	-.23	-.17	-.22	.04	-.12	.05
Number of health problems	.02	.26	.26	-.22	.21	-.19
Activity score	.02	-.18	-.18	.31	-.01	.28
Restricted/ repetitive behaviour score	.07	-.16	-.16	.17	-.06	.16
Severity score aggression	.17	-.20	-.20	.24	-.13	.20
Severity score destruction	.22	-.07	-.07	.21	.05	.20
Severity score self-injury	.17	.04	.04	.22	.09	.25
Parental depression	.05	.03	.02	.05	.07	.04
Parental anxiety	.18	.27	.23	.08	.27	.16

**Table 3:** Results of bootstrapped *t*-tests (adjusted where appropriate for unequal variance).

	Number of professionals			Cost of appointments		
	Community	Hospital	Combined	Community	Hospital	Combined
Gender	$t(47) = -.89,$ $p = .38$	$t(47) = .73,$ $p = .48$	$t(47) = -.89,$ $p = .38$	$t(47) = 1.49,$ $p = .14$	$t(47) = -.39,$ $p = .70$	$t(47) = .96,$ $p = .34$
Ethnic background	$t(46) = -1.94,$ $p = .06$	$t(46) = -.78,$ $p = .44$	$t(46) = -1.62,$ $p = .11$	$t(46) = -.45,$ $p = .64$	$t(46) = -.22,$ $p = .82$	$t(46) = -.47,$ $p = .64$
Diagnosis of autism	$t(47) = .76,$ $p = .45$	$t(47) = .81,$ $p = .73$	$t(47) = -.36,$ $p = .72$	$t(47) = .89,$ $p = .38$	$t(12.46) = 1.24,$ $p = .24$	$t(14.23) = 1.31,$ $p = .21$
Diagnosis of autistic traits	$t(29.1) = -10,$ $p = .31$	$t(44.4) = .149,$ $p = .14$	$t(42.7) = -1.24,$ $p = .22$	$t(47) = -.94,$ $p = .35$	$t(47) = -.72,$ $p = .47$	$t(47) = .46,$ $p = .64$

**Table 4:** Median and mean cost (£) of community and hospital appointments by topography of challenging behaviour (all analyses bootstrapped).

	n	Community Appointments					Hospital Appointments					All Appointments				Effect Size (d)	
		Median £ (IQR)	Mean £ (s)	t/F	p	Effect Size (d)	Median £ (IQR)	Mean £ (s)	t/F	p	Effect Size (d)	Median £ (IQR)	Mean £ (s)	t/F	p		
Aggression	Present	41	317.8 (384.7)	401.26 (345.9)	-	<	0.75	0 (92.7)	92.77 (222.2)	-	.77	0.10	321.4 (525.1)	494.03 (436.1)	-	.007	0.64
	Absent	8	142.7 (52.5)	161.76 (58.9)	4.09 <sup>1</sup>	.001		0 (178.8)	72.66 (123.6)	-0.27	.77	0.10	161.3 (187.1)	234.42 (164.6)	2.90 <sup>1</sup>	.007	0.64
Destruction of environment	Present	31	321.4 (386.6)	439.40 (372.4)	-	.01	0.67	0 (139.0)	115.22 (250.8)	-	.24	0.34	323.0 (928.9)	554.63 (472.3)	-	.006	0.71
	Absent	18	165.0 (189.7)	229.12 (176.6)	2.62 <sup>1</sup>	.01		0 (57.9)	45.16 (90.9)	1.19	.24	0.34	189.3 (237.4)	274.28 (196.9)	2.92	.006	0.71
Self-injurious behaviour	Present	33	321.4 (573.8)	449.32 (378.1)	-	.09	0.44	0 (139.0)	70.97 (110.6)	.64	.53	-0.18	345.0 (521.9)	520.29 (412.8)	-	.30	0.31
	Absent	26	189.1 (264.0)	285.05 (363.2)	1.76	.09		0 (57.9)	105.87 (268.3)	.64	.53	-0.18	235.6 (350.2)	390.92 (414.4)	1.04	.30	0.31
Forms of challenging behaviour	None	5	183.5 (97.5)	186.53 (57.30)				0 (156.0)	62.40 (139.5)				183.5 (253.5)	248.93 (192.8)			
	One	10	139.0 (155.6)	165.26 (121.3)	3.00	.04	0.63	0 (69.5)	40.82 (77.8)	0.57	.64	0.14	162.0 (281.3)	206.09 (134.6)	2.49	.07	0.27
	Two	17	317.8 (400.4)	395.66 (306.9)				0 (92.7)	140.84 (320.7)				323.0 (779.9)	536.85 (465.3)			
	Three	17	345.0 (685.7)	496.16 (408.2)				0 (157.8)	74.73 (119.8)				311.6 (759.9)	570.85 (454.0)			

<sup>1</sup>Equal variances not assumed