**Self-injurious, aggressive and destructive behavior in children with severe intellectual disability:**

**Prevalence, service need and service receipt in the UK**

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**Keywords: Aggression, self-injury, destruction, prevalence, intellectual disability, service need, service receipt.**

**Abstract**

Children with severe intellectual disabilities are at increased risk of presenting with self-injurious, aggressive and destructive behavior. Severity of these behaviors is an important predictor of psychological and behavioral service use by people with intellectual disabilities. However, studies suggest that the needs of children with intellectual disabilities and their families are not being met. The aims of the present study were to: (1) describe the self-injurious, aggressive and destructive behaviors and subsequent support needs of children with severe intellectual disabilities attending special schools in one major city within the UK, (2) compare teacher and primary carer ratings of behavior and service need and (3) explore the extent to which the needs of children with intellectual disabilities are being met in terms of contact with relevant specialist services. Questionnaires were completed by teachers and primary family carers of children with a severe intellectual disability. Results indicated that at least 5.3% and 4.1% of children showed at least one behavior at a clinically significant frequency and management difficulty respectively. Primary carers identified more children with significant behavior difficulties and support needs than teachers. The odds for children presenting with high levels of the behaviors of interest for having a service need for behavioral intervention were at least 13 times those for children not showing the behaviors, yet only doubled for contact with a specialist relevant health-care professional. These results quantify the magnitude of the substantial gap between level of need and relevant support received.

**1. Introduction**

Over the past decade there has been a growth in prevalence studies of the psychological and behavioral disorder experienced by children with intellectual disabilities. Although there is variation in sample size, measures used to ascertain caseness and other aspects of methodology, there is clear consensus that young people with intellectual disability are at much greater risk of emotional, mental health and behavioral difficulties in comparison to their peers without intellectual disability (Cormack, Brown, & Hastings, 2000; Emerson, Einfeld, & Stancliffe, 2010; Emerson, Robertson, & Wood, 2005; Kiernan & Kiernan, 1994). Within this group of children, those with more severe intellectual disabilities are at an increased risk of presenting with specific behavior disorders including self-injury and aggression, with estimates of between 10 and 45% of individuals displaying at least one form of this type of behavior (e.g. Borthwick-Duffy, 1994; Einfield & Tonge, 1996; Kiernan & Kiernan, 1994; Parmenter Einfeld, Tonge, & Dempster, 1998; Molteno, Molteno, Finchilescu & Dawes, 2001; Davies and Oliver, 2013). These behaviors are of particular interest in this group because causal models, assessments and interventions are well documented in the applied behavior analytic and related literatures. This invites study of the prevalence of these behaviors specifically, alongside examination of their severity and the need for and receipt of interventions.

There is an obvious value to prevalence studies conducted within administrative boundaries in that they can provide service planners and providers with information on which to base decisions about resources required. Additionally, they are valuable for furthering understanding of the nature and severity of the behaviors of interest. For example, associations between relevant variables to establish potential risk markers for particular behaviors can be explored (Chadwick, Walker, Bernard, & Taylor, 2000; Oliver et al., 2012; Richards, Oliver, Nelson & Moss, 2012). In order to ascertain a complete picture of the context and potential environmental influences on behaviors, it is important to gather information from a variety of sources (Tasse & Lecavalier, 2000; Emerson et al., 2005). However, owemost prevalence studies tend to report on children’s behavior within one environmental setting (i.e. home or school). There is value therefore of studies in more than one environment and that document differences in behavioral presentation and service need between these environments.

To date, few studies have compared the rates of problematic behaviors presented by children with intellectual disabilities across different environments. Tasse and Lecavalier (2000) used the French version of the Nisonger Child Behavior Rating Form (Aman, Tasse, Rojahn, & Hammer, 1996) to compare parent and teacher ratings of the behavior of 109 schoolchildren. Their results showed significant differences between parents and teachers on three problem behavior subscales in particular (i.e. conduct problems, insecure/anxious and hyperactive), with parents ratings on these subscales significantly higher than those for teachers. A more recent study by Emerson et al. (2005) also described differences between parents and teachers regarding 81 children’s behavior. They explored the emotional and behavioral needs of children with intellectual disabilities using the Communication and Physical Development scales of the Adaptive Behavior Scale (ABS: Lambert, Nihira, & Leland, 1993) and the Developmental Behaviour Checklist (DBC: Einfeld & Tonge, 1995), with higher ratings of behavior at home than school.

Emerson et al. (2005) suggest three possible explanations for these differences. First, they highlight the situational specific nature of difficult behaviors. For example, considering the needs of children with features of Autistic Spectrum Disorder, the structure of a school with predictable timetables and routines, physical space and availability of visual information may all be more readily available and influence behavior beneficially. Second, Emerson et al. suggest that different perceptions can be held by parents and teachers depending on the social and environmental consequences of behaviors. Third, parents and teachers may use different reference points for judging behavior. Further explanations may be linked to a difference between parents and teachers in the level of training received to understand and manage behavior, the levels of stress experienced which can impact on coping and hence perceived severity of the behaviors and real differences in the level of behaviors due to operant learning histories.

The severity of problem behavior is potentially an important predictor of psychological and behavioral service receipt by people with intellectual disabilities (Jacobson, 1998), yet studies suggest that the needs of children with intellectual disabilities and their families are not being adequately met. For example, Einfeld and Tonge (1996) surveyed 454 children in five regions of Australia using the Developmental Behaviour Checklist (Einfeld & Tonge, 1995). They included data on contact with professionals (i.e. one item on the DBC asks if “help has been sought for any behavior or emotional problems, apart from slow development, of the child or teenager in your care? If so, from whom?”). From the responses, only 9% of those children with definite psychiatric and emotional/behavioral disturbance received assistance from specialist professionals. Older studies in the UK also identify a shortfall of delivery of psychological services. Oliver, Murphy and Corbett (1987) for example reported that only 2% of those showing self-injury were in receipt of psychological services. However, there are few contemporary studies of service need and receipt.

In summary, there is a need to: 1) establish the prevalence of behaviors for which effective interventions are readily available within administrative boundaries relevant to service delivery (e.g. school provision), such as self-injury, aggression and destruction, in children with severe intellectual disability, 2) examine reported presence and severity of these behaviors across both home and school environments and 3) establish the need for and receipt of services in those showing the behaviors. Consequently, the aims of this study were to: 1) describe the frequency and management difficulty of self-injurious, aggressive and destructive behaviors in children with severe intellectual disabilities attending special schools in one major city in the UK, 2) compare the relevant behaviors and service need of these children as identified by teachers and primary carers and 3) describe the extent to which the needs of children with intellectual disabilities showing these behaviors are being met by way of contact with relevant specialist services.

**2. Methodology**

**2.1. Recruitment**

Sixteen special schools for children with intellectual disabilities in a large conurbation in the UK were approached for inclusion. These sixteen schools were all serving children with severe intellectual disability with access generally defined by substantial developmental delay coupled with problems with self-care and communication at a level likely to require supported living in the future. These schools therefore serve children with diverse needs but likely to be at high risk for the development of self-injurious, aggressive and other behaviours of interest. Of these, fourteen schools with a total of 1096 children with severe intellectual disabilities consented to participate. The two schools that declined to participate did so for administrative reasons.

**2.2. Participants** and procedure

Each school identified a co-ordinator who was responsible for the distribution of questionnaires to teachers and primary carers. Upon completion by teachers, a questionnaire pack was then sent to the relevant primary carers. To preserve the children’s anonymity to the research team, yet allow comparison of responses from primary carers and teachers for individual children, the co-ordinators assigned codes to each child. Primary carer questionnaire packs included return envelopes and contact details of the research team, with an assurance that interpreters could be arranged if required. Reminders to primary carers were placed in school newsletters three weeks after the distribution of questionnaire packs to them. Ethical review was provided by the University of Birmingham.

970 (89%) questionnaires were completed and returned by teachers. Children below the age of 4 (n = 17) and over 19 years (n = 10) were removed from the sample leaving a school-based total sample of 943 children. According to the questionnaire data, teachers had known the children between one month and 10 years (mean length of time: 9.9 months, *SD* = 12.3). From the 1096 questionnaires sent to primary carers at the child’s home, 361 (33%) were returned. The majority of primary carer questionnaires were completed by mothers and/or fathers (89%, including step-parents), with the rest completed by siblings (20, 5%) formal carers (8, 2%) by other relatives (6, 2%) and grandparents (4, 1%). A total of 296 children, between the ages of 4 years and 18 years 11 months, had two corresponding sets of data from both school and home. Data from both the total school sample (n = 943) and the primary carer/teacher comparison group (n = 296) will be analysed within the study.

**2.3. Measures**

The questionnaire packs for teachers and primary carers included a general background information sheet (age, gender and ethnicity), as well as measures of ability and service needs (as described below).

**2.3.1. Wessex Scales (Kushlick, Blunden, & Cox, 1973)**

This is a brief, reliable measure of disability that includes ratings of Mobility, Self-help, Continence, Literacy, Sensory Impairment and Verbal Skills. For each scale a total score can be calculated by summing the ratings for each item within that scale. The total score can subsequently be rated as one of three levels of disability (e.g. for the Continence scale a total score of 4, 5 or 6 indicates severely incontinent; sores of 7, 8 or 9 indicate moderate incontinence, and scores of 10, 11 or 12 indicates mild incontinence). A Behaviour scale was modified to rate frequency and level of management difficulty of three behaviors: self-injury, aggression to others, and destruction of property. Ratings were made based on a 5-point Likert scale (e.g. a rating of 1 representing a low management difficulty through to a rating of 5 representing a high management difficulty). Behavior scale items were deemed to be clinically significant if ratings of 4 or 5 were given for frequency of behavior and level of management difficulty. Inter-rater reliability of the modified Behaviour Scale was conducted by comparing the ratings of teachers and classroom assistants for 132 children (approximately 14% of the total sample). Kendall’s Tau values for frequency and management difficulty of behaviors ranged from .49 to .68 and .49 to .55 respectively.

**2.3.2. Service Needs Questionnaire**

This questionnaire aimed to ascertain teacher and primary carer perceptions of the level of support needed for each child in a range of areas (e.g. emotional, behavioral, educational, communication and medical needs). The amount of support needed in each area was rated on a Likert scale from 0 (no support needed) to 5 (a great deal of support needed). Ratings of 4 or 5 for the level of support required by the child in each of five areas (i.e. behavior support, daily life skills, communication, medical care, and education) were combined and recoded to indicate a significant support need. Inter-rater reliability analyses conducted using data from teachers and classroom assistants demonstrated the items to have significant Kendall Tau values ranging from .30 to .59. Open-ended responses were invited to the question *“In your opinion, what type of support does the/your child most need at this current time?”* The final question asked primary carers to identify which of the following professionals (Community Nurse, Psychiatrist, Paediatrician, Clinical Psychologist, Educational Psychologist, Social Worker, Speech and Language Therapist, Physiotherapist, Occupational Therapist, School Nurse, GP), if any, the child had had contact with during the last month .

**2.4. Data analysis and reduction**

Chi square, odds ratio and McNemar analyses were conducted. Results from odds ratio analyses were deemed significant if the lower confidence interval (CI) was greater than one. Where appropriate, Bonferroni corrections were applied.

**3. Results**

# 3.1 Participant characteristics

# Table 1 summarises the characteristics of the total sample group of children with severe intellectual disabilities for whom teachers completed questionnaire packs, and the characteristics of children within the primary carer/teacher comparison group. Information is included with reference to ethnicity, gender, and age as well as level of ability as calculated from the Wessex Scales (see Measures). For the purpose of analysis, children were split into two age bands: 4 years to 10 years and 11months, and 11 years to 18 years and 11 months. Approximately half of the overall sample were within each age band (55.4 percent and 44.6 percent, respectively).

*Insert Table 1 here.*

The return rates from each ethnic group between the total population sample and the primary carer/teacher comparison group sample were explored using chi-squared analyses to identify potential bias (by recoding data in each ethnic group to indicate for example, white/not white, in both samples/only in the total sample). For most ethnic groups no significant differences were identified, with the exception of White-British, Black African Caribbean and Pakistani groups. Compared to the total sample, there was a higher than expected return rate from White-British primary carers (2 (1, *N* =943) = 33.2, *p* < .001), and lower than expected return rates from Black African Caribbean (2 (1, *N* = 943) = 6.3, *p* < .05) and Pakistani (2 (1, *N* = 943) = 8.9, *p* < .01) primary carers in the comparison group. There were no significant differences in children’s age or gender between the two samples.

The ability levels of children on the Wessex scales in the comparison group sample (i.e. children with primary carer and teacher data) and the non-comparison group (i.e. children with teacher data only) were compared using independent t-tests. The Mobility scale showed a significant difference indicating that children in the comparison sample were more ambulant than children who were not in the comparison sample

**3.1. Behaviors and support needs of children from the total sample**

**3.1.1. Level of challenging behavior**

In order to describe the challenging behavior demonstrated by participants, the number of children from the total sample and across age groups, with clinically significant behaviors in terms of frequency and management difficulty was calculated (see Table 2).

*Insert Table 2 here.*

As demonstrated in table 2, at least 5.3% of children showed challenging behaviors at a clinically significant frequency whilst 4.1% (approximately 1 in 24) showed behaviors that are clinically significant in terms of management difficulty. Aggression was the most frequently demonstrated behavior and rated most difficult to manage both with the total sample and across age groups. Given that frequency and management difficulty ratings were highly correlated (i.e. Pearson’s *r* ranging from .77 to .87, *p*<.001), only frequency ratings of self-injury, aggression and destruction are presented in analyses from this point onwards.

To explore the association between age band and clinically significant frequency of behavior, a series of chi-squared analyses were performed for each behavior item. None of the calculations were of statistical significance, indicating no significant associations between age band and clinically significant self-injury, aggression, or destruction of the environment.

**3.1.2. Level of support**

To assess the level of support required by participants across domains, the number of children requiring a significant level of support with regard to behavior intervention, daily life skills, communication, medical care and education was calculated (see Table 3).

*Insert Table 3 here.*

As can be seen in Table 3, around a quarter of all participants required significant support with behavior intervention and medical issues, whilst more than half were rated as needing significant support with daily life skills, communication and education. Chi-square analysis demonstrated that, compared to the younger age group, older children required a significantly higher level of support with regard to the Daily Life Skills domain (2 (1, *N* = 943) = 6.75, *p* < .01). However, no significant differences across age groups were found with regard to the remaining four domains. Additionally, there were no significant gender differences for level of required support for each of the five domains, according to chi-square analysis.

Of those children rated by teachers as showing clinically significant behavior, the level of support needed regarding behavior management was explored further. Table 4 shows the number of children with clinically significant behavior who were also rated by teachers as requiring a significant level of behavior intervention support.

*Insert Table 4 here.*

As demonstrated in table 4, chi square analyses indicated a significant difference between frequency of behavior and level of behavior intervention required, so that children with high frequency self-injury (2 (1, *N* = 943) = 73.14, *p* < .001), aggression (2 (1, *N* = 943) = 178.63, *p* < .001) and destruction (2 (1, *N* = 943) = 99.89, *p* < .001) were significantly more likely to require behavior intervention than those with low frequency or no behavior. From an odds ratio analysis of these associations, it can be seen that the odds of children presenting with high levels of challenging behavior having a service need for behavior intervention are at least 13 times those for children not showing the behaviour.

**3.2. Comparison of behavior and support need ratings given by teachers and primary carers**

The frequency of teacher and primary carer ratings of high frequency behaviors and high level of support needs and discrepancies between them were calculated. McNemar analyses were also conducted to investigate the association between primary carer and teacher ratings of clinically significant behaviors and support needs (see Table 5).

*Insert Table 5 here.*

It is clear from Table 5 that primary carers identified significantly more children with significant behavior difficulties and support needs than teachers, with the exception of Education support needs.

Of those children rated by primary carers and teachers as showing clinically significant behavior, the level of service need for behavior intervention and management was explored further. Table 6 shows the number of children with clinically significant behavior who were also rated as requiring a significant level of behavioral intervention.

*Insert Table 6 here.*

The results of the chi square analyses demonstrated that children with frequent self-injury, aggression and destruction were rated as being in significantly greater need of behavior intervention and management

**3.3. Support provided by professionals and factors influencing access to health services**

The number of visits made to each of the professionals listed in the service needs questionnaire over the most recent one month period was calculated to examine the support provided to participants (see Table 7).

*Insert Table 7 here.*

In the last month, approximately half of the total sample had visited a GP, school nurse and speech and language therapist, whilst approximately a quarter had visited a physiotherapist, paediatrician and community nurse. To explore the association between children with at least one high frequency behavior and contact with at least one of three specialist health-care professionals who traditionally focus on behavior management (i.e. Clinical Psychologist, Community Nurse, and Psychiatrist), a chi-square test was performed. This analysis indicated that children with at least one high frequency behavior had greater contact with at least one of these professionals than children without such behaviors (2 (1, *N* = 296) = 7.09, *p* < .01). Analysis demonstrated that the odds of those children who have at least one clinically significant challenging behavior are having contact with a specialist health professional are twice those for children not showing these behaviours (OR=2; CI = 1.2; 3.4). Further chi-square analyses were conducted to explore the contact children with at least one clinically significant challenging behavior had had with other professional groups (e.g. GP, Speech and Language Therapists, Paediatricians and Social Workers). Most associations were not statistically significant, although there was a significant association between challenging behavior and contact with a Social Worker (2 (1, *N* = 361) = 7.3, *p* < .01). The odds of participants with at least one clinically significant challenging behavior having contact with a Social Worker were 2.3 times (CI = 1.25; 4.38) those for children not showing these behaviours.

**4. Discussion**

The aims of this study were to: 1) present prevalence data for a large city-wide population of children with severe intellectual disabilities attending schools for children with severe intellectual disability regarding behaviors of high frequency and severe management difficulty, as well as data regarding level of service need; 2) compare primary carer and teacher ratings of behaviors and support needs and 3) examine children’s contacts with relevant professionals as an indicator of service receipt.

In reporting the prevalence of challenging behavior in over 900 children with severe intellectual disabilities, this study is the largest of its kind. The large, school based sample of children living at home was also a major strength of this study, since it permitted the collection of data about children across two different environments who might have never come into contact with clinical services. The two schools that declined to participate did so for administrative reasons making it unlikely that the sample was unrepresentative. The assessment of children’s behavior from two sources, as in this study, is also recommended within the literature (e.g., Voelker, Shore, Hakim-Larson, & Bruner, 1997). Primary carer and teacher ratings were obtained simultaneously to minimize the effect of behavior change over time and make the ratings comparable. Inter-rater reliability was modest for some items but this might reflect real differences between raters with regard to perceived need, levels behaviour or functional differences for example.

The results indicated that across the total sample a significant minority of participants demonstrated challenging behavior which was clinically significant with regard to frequency and management. Of these, aggression was the most frequently demonstrated and most difficult behavior to manage. Although previous prevalence studies have used a variety of measures to determine psychopathology of children with severe intellectual disabilities, the rates found here are comparable to others (e.g. Einfeld & Tonge, 1996; Emerson, 2001; Kiernan & Kiernan, 1994). A quarter of the total sample was rated as requiring support regarding behavior intervention, further indicating the level of service need for this population (Allen, Lowe, Moore, & Brophy, 2007; Hallam & Trieman, 2001; Mansell, 1992). The amount of support regarding behavioral intervention also increased significantly with increased frequency of behavior, indicating the need for intervention.

When comparing the ratings of primary carers and teachers, the results indicated that parents identified significantly more children as showing higher frequency behaviors and requiring a higher level of support than teachers. The discrepancy between parent and teacher report is neither unusual nor unexpected. Over twenty years ago, a meta-analysis of 119 studies of emotional-behavioral problems in children without intellectual disabilities involving cross-informants showed a low correlation between parent and teacher ratings (Achenbach, McConaughy, & Howell, 1987). There are numerous plausible explanations for the discrepancy in primary carer and teacher ratings of behavior frequency and management. This finding could indicate a real difference in the behavior demonstrated by participants across the two environments. For example, children might show fewer behaviors at school where there are fewer potential triggers, such as lack of routine, or a different reinforcement history. It is also possible that higher primary caregiver ratings of behavior frequency represent their greater stress levels which may in turn affect how the behavior is perceived, experienced and managed. High levels of stress associated with caring for a child with intellectual disability and challenging behavior have been documented in the literature (Emerson, Robertson, & Wood, 2004).

One difference between the current study and others conducted previously in this area, is the attempt to gather data regarding children’s contacts with professionals, as an indicator of how well needs are being met. The data indicated that services had been recently accessed, although the perceived helpfulness of these was not assessed. Despite this apparent service use, the odds for children who presented with high levels of challenging behavior having a service need for behavior intervention were at least 13 times those for children who did not show this level of behaviour, yet the corresponding odds for contact with a relevant specialist health-care professional or social worker were only doubled. This demonstrates a substantial discrepancy between service need and receipt. Many factors influence the utilization of services including: scope and quantity of resources, eligibility criteria, treatment or service philosophy, changes in the locus of services as well as individual and family characteristics (Jacobson, 1998). The extent to which parents may be reluctant to seek help was not explored here.

Whilst these data have clinically significant utility for services for children with intellectual disabilities, a number of methodological issues must be considered. First the intellectual ability of the sample was loosely defined. Although participants were recruited from schools for children with a severe intellectual disability, it is likely that the resultant sample functioned on a range of moderate to severe intellectual disability. Therefore, caution needs to be exercised when generalising these results to the wider population of children with severe intellectual disabilities. Although interpreters were offered to all participants, none were requested. Bearing in mind the ethnically diverse population from which participants were recruited, it is likely that some primary carers did not take part because the study information was presented in English only, thus biasing the sample. Data regarding visits to relevant professionals were not verified with professionals but relied purely on the recollection of primary carers, so that it is likely that number of visits were underestimated. The low primary carer return rate might also have lead to an underestimation of the need however. Although it is difficult to make assumptions about why so many primary carers did not complete the questionnaire pack, possibilities are that these may have been families with fewer coping resources and whose children may have had more behavioral difficulties. Children with the most severe difficulties may also have been excluded or educated out of area in specialist placements.

An examination of broader family variables (e.g. parental depression/stress levels), which may also give clearer understanding of service need, was not within the scope of this study. Future research should focus on the characteristics of children, as well as their families, which increase the need for services. Ways in which services could better cater for the needs of children with intellectual disabilities and challenging behavior should also be considered, such as the utilisation of early intervention strategies.

**Acknowledgements:** The authors would like to thank Cerebra for partly funding this research. **5. References**

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# Table 1. Demographic information for the total school sample and primary carer/teacher comparison group

|  |  |  |
| --- | --- | --- |
| *Child**Characteristics* | Total sample (n = 943)n (%) | Parent/teacher comparison group(n = 296)n (%) |
| White-British | 446 (47.3) | 183 (61.8) |
| White-Other | 39 (4.1) | 7 (2.3) |
| Asian-Other | 11 (1.2) | 3 (1.0) |
| Bangladeshi | 34  (3.6) | 8 (2.7) |
| Black African-Caribbean | 47  (5.0) | 6 (2.0) |
| Black African | 15  (1.6) | 2 (0.6) |
| Indian | 39 (4.1) | 13  (4.3) |
| Pakistani | 227 (24.1) | 53 (17.9) |
| Mixed Parentage | 40 (4.2) | 16 (5.3) |
| Other | 19 2.0) | 1 (0.3) |
|  |  |  |
| Males | 589 (62.5) | 180  (60.8) |
| Mean age in years (sd) | 10.8  (3.8) | 10.7 (3.8) |
| Range of age in years | 4.0 – 18.8 | 4.0 – 18.4 |
| 4 – 10 years  | 522 (55.4) | 164 (55.4) |
| 11 -18 years  | 421 (44.6) | 132 (44.6) |
| Ambulant | 546 (57.9) | 185 (62.5) |
| Able in self-help skills | 398 (42.2) | 122 (41.3) |
| Continent | 438 (46.4) | 152 (51.4) |
| Literate (can read at least 3-4 word sentences) | 77 (8.2) | 24  (8.1) |
| Verbal (can speak in sentences of at least 3-4 words) | 417 (44.2) | 140(47.3) |
| No sensory impairment | 682(72.3) | 214 (72.3) |

**Table 2: Clinically significant behaviours of participants in total sample and across age groups**

|  |  |  |  |
| --- | --- | --- | --- |
|  | ***4 – 11 years (n=522)*** | ***11-18 years (n=421)*** | **Total Sample (n = 943)** |
|  | **High frequency****n**  **(%)** | **Severe management difficulty****n** **(%)** | **High frequency****n** **(%)** | **Severe management difficulty****n**  **(%)** | **High frequency****n**  **(%)** | **Severe management difficulty****n** **(%)** |
| **Self-injury** | 25 (4.7) | 19 (3.6) | 25 (5.9) | 20 (4.8) | 50 (5.3) | 39 (4.1) |
| **Aggression** | 60 (11.5) | 44 (8.4) | 42 (9.9) | 37 (8.8) | 102 (10.8) | 81 (8.6) |
| **Destruction** | 45(8.6) | 31 (5.9) | 24 (5.7) | 24 (5.7) | 69 (7.3) | 55 (5.8) |

**Table 3. Participants from the total sample requiring a high degree of support across domains**

|  |  |  |  |
| --- | --- | --- | --- |
|  | 4 – 11 yearsn (%) | 11 – 18 yearsn (%) | Total n (%) |
| Behaviour intervention | 149 (28.5) | 122 (29.0) | 271 (28.7) |
| Daily life skills | 242 (46.4) | 231(54.9) | 473(50.2) |
| Communication | 316 (60.5) | 241(57.2) | 557 (59.1) |
| Medical support | 119 (22.8) | 110 (26.1) | 229 (24.3) |
| Education | 398 (76.2) | 329 (78.1) | 727 (77.1) |

**Table 4. Participants with high frequency behaviours requiring significant behaviour support within the total school sample and across age groups.**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 4 – 10 yearsn (%) | 11 – 18 years n (%) | Totaln (%) | Chi (*p* value) | Odds ratio (CI ) |
| Significant self-injury | 20(80) | 21(84) | 41(82) | 73.14 <.001 | 13.1 (6.3; 27.4) |
| Significant aggression | 47(78) | 40(95) | 87(85) | 178.63<.001 | 20.7(11.7; 36.7) |
| Significant destruction | 35(78) | 21(88) | 56(81) | 99.89<.001 | 13.2 (7.1; 24.6)  |

**(Odds ratios and chi-square analyses refer to comparison of all children requiring behaviour support with vs. without high frequency behaviour)**

**Table 5. Teacher and primary carer ratings of high frequency behaviours and high level of support needs (n = 296)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Teacher ratings of high frequency (%) | Primary carer ratings of high frequency (%) | Teacher rated frequency as high when primary carer did not. (%) | Primary carer rated frequency as high when teacher did not. (%) | McNemar (*p)* |
| Behaviours:*Self-injury* | 5.1  | 19.6 | 40.0 | 84.5 | <.001 |
| *Aggression* | 9.8 | 20.9 | 69.0 | 85.5 | <.001 |
| *Destruction* | 7.4 | 24.7 | 50.0 | 84.9 | <.001 |
|  |  |  |  |  |  |
| Support needs: |  |  |  |  |  |
| *Behaviour*  | 30.4 | 49.0 | 36.7 | 60.7 | <.001 |
| *Daily life skills* | 44.9 | 67.2 | 24.1 | 49.2 | <.001 |
| *Communication* | 58.1 | 66.9 | 18.6 | 29.3 | <.01 |
| *Medical* | 19.9 | 43.6 | 42.4 | 73.6 | <.001 |
| *Education* | 78.7 | 79.4 | 19.7 | 20.4 | .918 |

**Table 6. Participants with high frequency behaviours needing significant behaviour support as rated by primary carers and teachers.**

|  |  |  |
| --- | --- | --- |
|  | High level of behaviour support needed |  |
|  | 4 – 11 yearsn (%) | 11 – 18 yearsn (%) | Totaln (%) | Chi square(*p* value) |
| ***Parents:***Significant Self-injury | 27 (87) | 18 (72) | 45 (80) | 18.6 ( < .001) |
| Significant aggression | 26 (79) | 19 (73) | 45 (76) | 13.7 (< .001) |
| Significant destruction | 37 (79) | 24 (92) | 61 (84) | 32.6 (<.001) |
| ***Teachers:***Significant self-injury | 6(100) | 7(100) | 13(100) | 28.3(<.001) |
| Significant aggression | 12(92) | 16(100) | 28(97) | 60.6(<.001) |
| Significant destruction | 11(85) | 9(100) | 20(91) | 36.9(<.001) |

###### (Chi-square analyses refer to comparison of all children requiring high level of behaviour support with vs. without clinically significant behaviour)

###### Table 7. Number and percentage of participant visiting professionals over the most recent one month period (main carer report, n=296)

|  |  |  |  |
| --- | --- | --- | --- |
|  | 4 – 11 yearsn(%) | 11-18 yearsn(%) | Totaln(%) |
| Community Nurse \* | 28 (17.6) | 38 (27.0) | 66 (22.0) |
| Psychiatrist \* | 7 (4.4) | 11 (7.8) | 18 (6.0) |
| Paediatrician | 53 (33.3) | 33 (23.4) | 86 (28.7) |
| Clinical Psychologist \* | 6 (3.8) | 10 (7.1) | 16 (5.3) |
| Educational Psychologist | 14 (8.8) | 16 (11.3) | 30 (10.0) |
| Social Worker | 26 (16.4) | 22 (15.6) | 48 (16.0) |
| Speech and Language  | 85 (53.5) | 51 (36.2) | 136(45.3) |
| Physiotherapist | 39 (24.5) | 42 (29.8) | 81 (27.0) |
| Occupational Therapist | 19 (11.9) | 18 (12.8) | 56 (18.7) |
| School Nurse | 74 (46.5) | 82 (58.2) | 156(52.0) |
| GP | 84 (52.8) | 64 (45.4) | 148(49.3) |

\* Professionals deemed to typically offer support regarding behaviour intervention.