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Self-injury, aggression and destruction in children with severe intellectual disability: Incidence, persistence and novel, predictive behavioral risk markers.

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Abstract

Background; A risk informed, early intervention strategy for self-injurious, aggressive and destructive behaviours in children with severe intellectual disability is gaining support. The aims of this study were to establish the cumulative incidence and persistence of self-injury, aggression and destruction and the relationship between these behaviours and two potentially predictive behavioural risk markers (repetitive behaviour, and impulsivity and overactivity) in children at high risk.

Methods; In a longitudinal design self-injury, aggression and destruction were assessed by teachers of 417 children with severe intellectual disability on two occasions separated by 15 to 18 months.

Results; Aggression, destruction and self-injury were persistent (69%, 57% and 58% respectively). Repetitive and restricted behaviours and interests (RRBI) and overactivity/impulsivity (O/I) were significantly associated with aggression (O/I OR = 1.291, $p < .001$), destruction (RRBI OR 1.201, $p = .013$; O/I OR 1.278, $p < .001$) and/or self-injury (RRBI, OR 1.25, $p = .004$; O/I OR = 1.117, $p < .001$). The relative risk of the cumulative incidence of self-injury, aggression and destruction was significantly increased by repetitive and restricted behaviours and interests (self-injury 2.66, destruction 2.16) and/or overactivity/impulsivity (aggression 2.42, destruction 2.07).

Conclusions; The results provide evidence that repetitive and restricted behaviours and interests, and overactivity/impulsivity, are risk markers for the onset of self-injury, aggression and destruction within the already high risk group of children with severe intellectual disability.

1.1 Introduction

Prevalence rates of challenging behaviour in people with intellectual disabilities are as high as 45% with limited data on incidence (Emerson et al., 2001a; Grey et al., 2010; Lowe et al., 2007). Negative consequences are well documented and include physical harm, exclusion from services, distress for families and costly services (Kiernan & Qureshi, 1993; Knapp, Comas-Herrera, Astin, Beecham, & Pendaries, 2005; Konarski, Sutton, & Humman, 1997; McIntyre, Blacher, & Baker, 2002; Nissen & Haveman, 1997). Generally, the prevalence of challenging behaviour increases with age until early adulthood, and is persistent over time with reported rates between 57 and 90% (Chadwick et al., 2004; Davies & Oliver, 2013; Emerson et al., 2001b; Kebbon & Windahl, 1986; Kiernan & Alborz, 1996; Murphy et al., 1993; Nottestad & Linaker, 2002; Taylor, Oliver, & Murphy, 2011). However, data on the persistence of these behaviours in children are not available.

The high prevalence and persistence of challenging behaviour and the paucity of effective and economically viable interventions have generated support for early intervention strategies (Richman, 2008; Richman & Lindauer, 2005; Symons, Sperry, Dropik, & Bodfish, 2005). By intervening early, interventions would, arguably, be less difficult to implement as the behaviour would be easier to manage. Early intervention strategies can be informed by empirically supported models of the development of behaviours such as self-injury (Guess & Carr, 1991; Oliver 1995). These models differentiate between variables and causal factors related to the onset, maintenance, trajectory and severity of challenging behaviour and hence indicate different points for intervention and prevention of increasing severity at different stages. In order to implement an early intervention strategy efficiently, services might target children at highest risk. Several child characteristics are associated with challenging behaviour and might therefore predict future presence and/or severity. Chadwick, Piroth,

Walker, Bernard and Taylor (2000) identified an association between greater severity of intellectual disability and destructive and self-injurious behaviour. This finding was replicated in three further studies, which also identified the importance of autism, lower chronological age (Baghdadli, Pascal, Grisis, & Aussilloux, 2003) and communicative ability (Holden & Gitlesen, 2006; McClintock, Hall, & Oliver, 2003). Some genetic syndromes are also associated with quantifiable risk for the development of self-injury and aggression (Arron et al., 2011). More recently, two longitudinal studies have identified significant associations between self-injury and communicative ability (Danquah et al., 2009) and autism (Baghdadli et al., 2008). Finally, whilst investigating the early development of self-injurious behaviour, Murphy, Hall, Oliver, & Kissi-Debra (1999) reported an association between an increase in self-injurious behaviour and teachers' concern regarding this behaviour 18 months previously, and an association between operant reinforcement processes and increase in self-injury over a two year period (Oliver et al., 2005). In combination, these characteristics and predictors may have value for identifying children at the highest risk for the development of severe challenging behaviour, particularly when combined with data on incidence and persistence.

Recent studies have focused on specific behavioural markers associated with challenging behaviour in children within this already higher risk group characterised by severe intellectual disability. Illustrating this, Oliver et al. (2012) reported associations between repetitive, ritualistic and presence and severity of self-injury and aggression, a finding replicated in children with Cornelia de Lange Syndrome (Oliver, Sloneem, Hall, & Arron, 2009), supported by a review (Petty & Oliver, 2005) and recent studies of children and adults with genetic syndromes (Arron, Oliver, Berg, Moss, & Burbidge, 2011), and autism spectrum disorder (Richards et al., 2012). A recent study also found that overactive and impulsive

behaviours significantly predicted both the presence and severity of challenging behaviour in very young children (Petty et al., 2013). Substantiating the importance of impulsivity and overactivity, two further studies have identified associations between self-injurious and aggressive behaviour with attention deficit hyperactivity disorder (Cooper, Smiley, Allan et al., 2009; Cooper, Smiley, Jackson et al., 2009). In combination, these studies allude to the possibility that the behavioural markers of repetitive behaviour and overactivity\impulsivity might predict the future development of self-injurious and aggressive behaviour within children with the existing risk marker of severe intellectual disability.

To date, studies in this area involve lengthy assessments that might not be appropriate when screening large populations, as would be required for an early intervention strategy in clinical settings. Studies have also examined the association between behavioural correlates and various challenging behaviours at one point in time only, so there are few longitudinal data. Thus, the aims of this study were to use a brief screening questionnaire (Self-injury, Aggression and Destruction Screening Questionnaire (SAD-SQ)), appropriate for use in clinical settings, to establish:

1) The prevalence, cumulative incidence, persistence and remission of self-injury, aggression and destruction in children with severe intellectual disability aged 12 and under.

2) The relationship between self-injury, aggression and destruction, and the possible behavioural risk markers of repetitive behaviour, impulsivity and overactivity, at the same time and over time.

1.2 Method

1.2.1 Development of the Self-injury, Aggression and Destruction Screening Questionnaire (SAD-SQ)

The SAD-SQ is a short and accessible measure of behavioural risk markers known to be associated with challenging behaviour, including age, severity of intellectual disability, repetitive and restricted behaviours and interests, overactive and impulsive behaviour, as well as three specific forms of challenging behaviour, namely self-injury, aggression and destruction. Items related to health are also included with the SAD-SQ but were not analysed as part of this study.

Two versions of the screen were developed; under 6 years and 6 years and over, with 54 and 64 items respectively. Items used were in a Likert, binary yes/no and short answer format. Each version differed only in measurement of severity of intellectual disability; using twenty items from the Denver Developmental Screening Test II (DDST II; Frankenburg, Dodds, Archer, Shapiro, & Bresnick, 1992) and three items from the Wessex Behaviour Scale (Kushlick, Blunden, & Cox, 1973) for children aged less than six and six years and over respectively. Four items from the Activity Questionnaire (Burbidge et al., 2010) pertaining to difficulties waiting, acting as if driven by a motor, wanting things immediately and finding it difficult to hold still were used in order to assess overactive and impulsive behaviour. Two items from the behaviour and emotional difficulties section of the Self-Help and Behaviour Rating Scale (Petty, 2006) pertaining to repetitive movements as well as obsessions and rituals were used to assess frequency and severity of repetitive and restricted behaviour. This scale is an adapted version of the Wessex Behaviour Scale (Kushlick et al., 1973). Examples of each type of challenging behaviour were provided in order to help define them (to

illustrate, punching, pushing, kicking, pulling hair and grabbing clothing were given as examples of aggression). Questions within the SAD-SQ referred to a one month time frame. The format of questions within the SAQ-SQ related to severity or frequency of occurrence of behaviours were in a Likert scale format.

Davies and Oliver (In review) report good reliability, as well as concurrent and convergent validity of the SAD-SQ. To illustrate, inter-rater reliability ranged from .21 to .47 (only overactvity/impulsivity was low at .06 which is not uncommon within the literature; Amador-Campos, Forns-Santacana, Guardia-Olmos & Pero-Cebollero, 2006). Illustrating the convergent validity of the SAD-SQ, "high risk" participants (15 highest scoring recruited participants) scored significantly higher on other standardised measures of the putative risk markers overactivity (U = 33, p = .001), impulsiveness (Z = - 2.727, $p < .008$), repetitive (U = .49, p = .003) and restricted (U = 61.5, p = .017) behaviours than low risk participants (15 lowest scoring recruited participants).

1.2.2 Recruitment

Schools catering for children with a severe intellectual disability between the ages of 2 and 12 years local to the research site were invited to participate. All participants who participated at screen (T1) were traced 15 to 18 months later (T2) (mean follow up time 16.5 months).

1.2.2.1 Participants

Six hundred and twenty nine children attending fourteen schools for children with a severe intellectual disability participated. At T1, mean age of participants was 7.33 years (ranging from 2-12); 62.5% of the sample was male and 34.3% had a genetic syndrome. Data from the

Wessex indicated that at T1, the majority had some speech (62.5%), normal vision (68.9%), normal sight (87.9%) and were ambulant (72.2%). The return rate of the SAD-SQ at T1 was estimated at 85%. Twelve of the original schools and 66.3% of the original sample participated at T2, resulting in a sample size of 417 participants. The return rate at T2 was 79%, with missing data (over 25% of items missing) also contributing to attrition (50 participants). Participants at T2 had a mean age of 8.56 years (ranging from 4-14). 61% were male, 20% were identified as having a genetic syndrome (4.8% reported to have Down's Syndrome).

1.2.3 Procedure

Letters and information sheets were sent to parents of all children between the ages of 2 and 12 years in participating schools. A SAD-SQ was completed regarding each child whose parents had not withdrawn informed consent from the study three weeks after receipt of the information pack. Participating schools were sent a SAD-SQ for every eligible child in the school and returned upon completion by class teachers. Teachers were chosen for screen completion due to poor return rates from parents experienced in previous studies (Petty, 2006).

Schools which participated at T1 were contacted 15 to 18 months later to arrange for SAD-SQ completion. In instances where children had moved to other schools within the UK, headteachers were asked to help trace the current location.

1.2 4 Data analysis

In order to assess severity of intellectual disability as a risk marker for challenging behaviour, disability percentile scores were calculated to generate comparable Denver and Wessex

scores. Greater and lesser severity of intellectual disability groups were formed using median splits on these disability percentile data for both the under 6 and 6 years and older groups and then combined to form one high and low group for the whole sample.

When examining basic group comparisons, parametric tests were used unless the data were not normally distributed. Bonferonni corrected Cramer's phi tests were conducted in order to examine the persistence of both the putative risk markers and challenging behaviour. Relative risk and Mann Whitney U analyses were conducted to measure the associations between each putative risk marker and the presence and severity of challenging behaviour at T1. Relative risk analysis was also conducted to examine the ability of the putative risk markers to predict the presence of challenging behaviour 18 months later, and particularly the remission, cumulative incidence and persistence of challenging behaviour. Relative risks were deemed significant if the lower confidence interval was greater than one. Relative risks were used as opposed to odds ratio due to greater ease of interpretation and reduced likelihood of overestimating risk (Schmidt & Kohlmann, 2008). Because of the large number of relative risk tests conducted, 99.9% confidence intervals ($p<.001$) were used. Finally, a series of binary logistic regressions was also conducted to control for the potentially confounding overlap between variables in the relative risk analysis and to test the theoretical predictive models developed for the presence of challenging behaviour. Bonferonni corrections were applied to the Alpha levels for these analyses.

1.3 Results

To ensure that the T2 sample was representative of the T1 sample a series of Mann Whitney U and χ^2 analyses were conducted to detect possible significant differences between participants included in the T2 (417) and those from the T1 sample who were not. This

analysis revealed that the T2 participants were significantly younger than the participants who were not included (U = 33559, $p < .001$). The T2 participants also had a significantly more severe intellectual disability than the participants who were not included (U = 35886, $p = .002$). There were no significant differences between groups with regard to the behavioural correlates repetitive and restricted behaviours and interests and overactivity/impulsivity. Similarly, no significant differences between these groups in terms of frequency or severity of behaviours were found, except for aggression (χ^2 (1, $N = 30$) = 3.27, $p < .05$), the frequency of which was greater in the T2 sample, than participants who were not included. These results indicate that the T2 participants were generally representative of the original participants.

1.3.1 Association between child characteristics and self-injury, aggression and destruction

The relative risk of self-injury, aggression and destruction given the gender and severity of intellectual disability was examined across the total sample and two median split age groups (7 years and under and 8 years and over) at T1 to examine the association between these child characteristics and self-injury, aggression and destruction (see Table 1).

+++++ INSERT TABLE 1 HERE +++++

The relative risk of self-injury, aggression or destruction was not significantly different given severity of intellectual disability or gender. Differences in results across age groups indicated the potential importance of age as a putative risk marker for these behaviours. However, when entered into the relative risk analysis as a factor, age was not significantly associated with aggression (RR = 1.3, CI = .91, 1.87), destruction (RR = .95, CI = .54, 1.7), self-injury

(RR = 1.11, CI = .65, 1.92) or one or more behaviours (RR = 1.15, CI = .85, 1.56), with no significant difference in the relative risk of these behaviours in participants aged 7 years and under and 8 years and over (CI = 99.9%). These results indicated that gender, severity of intellectual disability and age were not significantly associated with self-injury, aggression or destruction.

1.3.2 The cumulative incidence, remission and persistence of self-injury, aggression and destruction

In order to examine the cumulative incidence (with 16.5 month mean follow up time), remission and persistence of self-injury, aggression and destruction, the percentage of the sample who showed these behaviours at T2 but not T1, T1 but not T2 and both or neither T1 nor T2 respectively was calculated (see Table 2).

+++++ INSERT TABLE 2 HERE +++++

The Cramer's phi analysis shown in Table 2 indicates that self-injury, aggression and destruction were highly stable across the 15 to 18 month follow up period. For all forms of behaviour, the majority of participants either continued to demonstrate a behaviour or still did not show it. Aggression was the most persistent behaviour, with over 69% of participants demonstrating aggression at T1 showing the behaviour at follow up. With regard to any behaviour, over 70% of participants persisted in their demonstration of these behaviours.

1.3.3 Association between behavioural correlates and self-injury, aggression and destruction at T1

The risk of self-injury, aggression and destruction at T1 given the presence of the behavioural correlates at T1 using relative risk analysis was examined, as illustrated in Figure 1 (left column). As expected, the results demonstrate that the behavioural correlates were significantly associated with each target behaviour at T1. The relative risk of destruction given the presence of overactivity/impulsivity was particularly high. In order to control for the overlap between variables and to produce separate models of self-injury, aggression and destruction, a series of binary logistic regressions was conducted. The results of these analyses, also shown in Figure 1, show that each of the models significantly predicted self-injury, aggression and destruction at T1. Aggression, destruction, self-injury and one or more behaviours were all significantly predicted by overactivity/impulsivity. Repetitive and restricted behaviours and interests significantly predicted all behaviours except aggression.

+++++ INSERT FIGURE 1 HERE +++++

1.3.4 Prediction of self-injury, aggression and destruction at T2 from behavioural correlates at T1

The capacity for the behavioural correlates, repetitive and restricted behaviours and interests and overactivity/impulsivity, at T1, to significantly predict the presence of self-injury, aggression and destruction at T2 was examined using relative risk analyses (see Figure 2). The results indicate that the relative risk of the presence of self-injury, aggression and destruction at T2 given the presence of the behavioural correlates at T1, was significantly increased, with the exception of self-injury, the relative risk of which was not increased by the presence of overactivity/impulsivity. Whilst there was some variation in the extent to

which each behavioural correlate increased the relative risk of self-injury, aggression and destruction, the majority of the analyses indicated that the risk of each behaviour was approximately doubled given repetitive and restricted behaviours and interests or overactivity/impulsivity.

In order to control for the overlap between variables a series of binary logistic regressions was conducted, examining associations between repetitive and restricted behaviours and interests and overactivity/impulsivity at T1 and the presence of each target behaviour at follow up. If the relative risk of a form of challenging behaviour was significantly greater in participants with the behavioural correlates, it was entered into the regression analysis as a predictor variable. The results of this analysis are illustrated in Figure 2.

+++++ INSERT FIGURE 2 HERE +++++

As demonstrated in Figure 2, each of the models significantly predicted self-injury, aggression and destruction, as well as the presence of one or more behaviours.

1.3.5 Persistence of the behavioural correlates

Cramer's phi was used in order to examine the persistence of the behavioural correlates between T1 and T2. This analysis showed that, as predicted, each behavioural correlate was persistent across the 15 to 18 month period (Table 3).

+++++ INSERT TABLE 3 HERE +++++

1.3.6 The ability of the behavioural correlates to predict the remission, cumulative incidence and persistence of self-injury, aggression and destruction

Relative risk analyses were conducted to investigate whether repetitive and restricted behaviours and interests and overactivity/impulsivity were significant predictors of the remission, cumulative incidence or persistence of self-injury, aggression and destruction. Within this analysis, comparisons were made between participants in the no behaviour and cumulative incidence groups and the remission and persistence groups (Table 4).

+++++ INSERT TABLE 4 HERE +++++

As demonstrated in Table 4, repetitive and restricted behaviours and interests significantly predicted the cumulative (16.5 month mean follow up) incidence of self-injury, destruction and one or more behaviours, whilst overactivity/impulsivity significantly predicted the cumulative incidence of aggression and destruction. Thus, the predictors of cumulative incidence differ across target behaviours. Neither behavioural correlate significantly predicted the persistence of self-injury, aggression or destruction.

1.4 Discussion

The aims of this study were to establish the prevalence, cumulative incidence, persistence and remission of self-injury, aggression and destruction. The relationship between these behaviours and the behavioural correlates, repetitive and restricted behaviours and interests and overactivity/impulsivity was also examined at one point in time and over time, in a large sample of young children with severe intellectual disability. By employing a large, representative sample, almost two thirds of whom were retained at follow up, and a reliable,

brief measure, it is likely that the results of this study are generalisable to the population of children with a severe intellectual disability.

The results of this study demonstrate stability of self-injury, aggression and destruction over a 15 to 18 month period, so that, for all forms of behaviour, the majority of participants either continued to demonstrate a behaviour or still did not show it. These data are consistent with those of previous studies indicating the persistence of these behaviours (Chadwick, Kusel, Cuddy, & Taylor, 2004; Emerson et al., 2001b; Kebbon & Windahl, 1986; Murphy et al., 1993; Nottestad & Linaker, 2002).

At time 1, severity of intellectual disability, age and gender were not significantly associated with self-injury, aggression or destruction. Given the sample's small age range and severe level of intellectual disability, these results are unsurprising and thus do not necessarily contradict existing literature which has found severity of intellectual disability to be a risk factor for challenging behaviour in studies including older participants (e.g. Holden & Gitlesen, 2006). Other studies employing a sample of children with a severe intellectual disability have also reported no significant association between severity of intellectual disability and these behaviours within the severe intellectual disability group (Oliver et al., 2012). Although a recent review has reported a significant increase in the prevalence of self-injury and aggression with age, this was into mid-adulthood and thus potentially too late to be captured within this study (Davies & Oliver, 2013). Evidence of an association between gender and self-injury, aggression and destruction is mixed within the literature (Holden & Gitlesen, 2006; McClintock et al., 2003). In contrast, the behavioural correlates, repetitive and restricted behaviours and interests and overactivity/impulsivity were significantly associated with all behaviours, indicating their potential as risk markers. The predictive

models from the time 1 data for self-injury, aggression and destruction were also significant, with both behavioural correlates significantly predicting the presence of behaviours, except aggression which was significantly predicted by overactivity/impulsivity only. At time 2, the relative risk of aggression and destruction increased significantly given both behavioural correlates, only repetitive and restricted behaviours and interests significantly predicted self-injury. The predictive models for self-injury, aggression and destruction given the behavioural correlates at time 1 were also significant. With regard to the behavioural correlates, the results indicated that these too were stable over time. Repetitive and restricted behaviours and interests significantly predicted the cumulative incidence of self-injury, destruction and one or more behaviours, whilst overactivity/impulsivity significantly predicted the cumulative incidence of aggression and destruction. Neither of the behavioural correlates significantly predicted the persistence of self-injury, aggression or destruction.

These results replicate previous findings of an association between repetitive behaviour and self-injury, overactivity and destruction (Oliver et al., 2012; Petty et al., 2013) and extend these by identifying further associations between the behavioural correlates and challenging behaviours at both one point in time and over a 15 to 18 month period, illustrating the importance of these as risk markers. The association between the behavioural correlates of self-injury, aggression and destruction also implies a potential role for compromised behavioural inhibition in challenging behaviour in this population. This supposition is supported by contemporary neuropsychological models of ADHD and autism proposed by Barkley (1997a, 1997b), Sonuga-Barke (2002) and Turner (1997, 1999) which have indicated an association between repetitive behaviour, impulsivity, hyperactivity and poor inhibition. This could also complement operant models (e.g. Oliver and Richards, In review; Oliver, Hall, & Murphy, 2005) of challenging behaviour in which challenging behaviour is evoked

under stimulus conditions and reinforced so that the challenging behaviour becomes a learned response. Children with compromised behavioural inhibition might be compromised in their ability to inhibit this learned response and thus might show more frequent challenging behaviour, such as aggression. Therefore, repetitive behaviour might act as a risk marker in a number of ways; introducing a behaviour into the repertoire which can be shaped by operant processes into self-injury and by indicating an underlying inhibition deficit which makes it harder for children to suppress a learned response, such as aggression.

In order to explain the association between repetitive and restricted behaviours and interests and self-injury Guess and Carr's (1991) model is pertinent. Within this model, repetitive behaviour evolves into self-injury under the influence of social reinforcement. Thus, repetitive behaviours, which are common in children with intellectual disabilities (Chadwick et al., 2004; Thompson & Reid, 2002), introduce potential self-injury into the behavioural repertoire. This would explain how repetitive and restricted behaviours are associated with the introduction, but not persistence of self-injury. To date, the developmental trajectory of aggression has not been well documented, and thus the specific association between overactivity/impulsivity and aggression is not well understood. The results of this study also indicate a specific association between the different behavioural correlates and self-injury, aggression and destruction, indicating a specific developmental trajectory for these. These results also support the notion that factors contributing to the incidence of challenging behaviour are different to those aiding to maintain the demonstration of aggression, self-injury and destruction. It could be hypothesised that once working to introduce challenging behaviour into the behavioural repertoire, reinforcement supersedes the role of risk markers in the persistence of the behaviour.

Limitations of this study include the potential overlap between aggression, self-injury and destruction common within children with intellectual disabilities (e.g. Oliver et al., 2012) and thus also within studies investigating challenging behaviour in this population. This issue requires careful consideration in future research which might examine specific developmental trajectories for specific behaviours such as self-injury and aggression. The arbitrarily defined nature of the sample, recruited from schools for children with a severe intellectual disability, is also a limitation of the study, since heterogeneity with regard to severity of intellectual disability within the sample is likely.

In terms of the clinical implications of this study, longitudinal evidence has now been provided for the behavioural correlates, repetitive and restricted behaviours and interests and overactivity/impulsivity, so that they might, with increased confidence, be accepted and labelled as risk markers. Within an early intervention strategy, children with these risk markers could be identified to receive targeted interventions. For example, children with repetitive or impulsive behaviour could be closely monitored for the incidence of challenging behaviour and be quickly provided with behavioural interventions should challenging behaviour be observed, in line with the evidence base (e.g. Kahng, Iwata & Lewins, 2002). However, before identification of children at risk based on these risk markers occurs, data regarding the clinical utility of the screen are required.

References

Amador-Campos, J. A., Forns-Santacana, M., Guardia-Olmos, J., & Pero-Cebollero, M. (2006). DSM-IV Attention Deficit Hyperactivity Disorder Symptoms: agreement between informants in prevalence and factor structure at different ages. *Journal of Psychopathology and Behavioral Assessment, 28,* 23-32.

Arron, K., Oliver, C., Berg, K., Moss, J., & Burbidge, C. (2011). Prevalence and phenomenology of self-injurious and aggressive behaviour in genetic syndromes. *Journal of Intellectual Disability Research*, 55, 109-120.

Baghdadli, A., Pascal, C., Grisis, S., & Aussilloux, C. (2003). Risk factors for self-injurious behaviour among 222 young children with autistic disorders. *Journal of Intellectual Disability Research, 47,* 622-627.

Baghdadli, A., Picot, M. C., Pry, R., Michelon, C., Burzstejn, C., Lazartigues, A., & Aussilloux, C. (2008). What factors are related to a negative outcome of self-injurious behaviour during childhood in pervasive developmental disorders? *Journal of Applied Research, 21,* 142-149.

Barkley, R. A. (1997a). Behavioural inhibition, sustained attention and executive functions: constructing a unifying theory of ADHD. *Psychological Bulletin, 121, 65-94.*

Barkley, R. A. (1997b). *ADHD and the Nature of Self-Control.* New York: The Guildford Press.

Burbidge, C., Oliver, C., Moss, J., Arron, K., Berg, K., Hill, L., Trusler, K., Furniss, F., & Woodcock, K. A. (2010). The association between repetitive behaviours, impulsivity and hyperactivity in people with intellectual disability. *Journal of Intellectual Disability Research*, 54, 1078-1092.

Chadwick, O., Piroth, N., Walker, J., Bernard, S., & Taylor, E. (2000). Factors affecting the risk of behaviour problems in children with severe intellectual disability. *Journal of Intellectual Disability Research, 44,* 108-123.

Chadwick, O., Kusel, Y., Cuddy, M., & Taylor, E. (2004). Psychiatric diagnoses and behaviour problems from childhood to early adolescence in young people with severe intellectual disabilities. *Psychological Medicine, 35,* 751-60.

Cooper, S.-A., Smiley, E., Allan, L. M., Jackson, A., Finlayson, J., Mantry, D. *et al.* (2009). Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour, and related factors. *Journal of Intellectual Disability Research, 53,* 200-216.

Cooper, S.- A., Smiley, E., Jackson, A., Finlayson, J., Allan, L., Mantry, D. *et al*. (2009). Adults with intellectual disabilities: prevalence, incidence and remission of aggressive behaviour and related factors. *Journal of Intellectual Disability Research, 53,* 217-232.

Danquah, A., Limb, K., Chapman, M., Burke, C., Flood, A., Gore, S. *et al*. (2009). An investigation of factors predictve of continued self-injurious behaviour in an intellectual disability service. *Journal of Applied Research in Intellectual Disabilities, 22,* 395-399.

Davies, L. & Oliver, C. (2013). Age related prevalence of aggression and self-injury in persons with an intellectual disability. *Research in Developmental Disabilities, 34*, 764-775.

Davies, L. & Oliver, C. (In review). Screening for Risk for the Development of Challenging Behaviour in Children with Severe Intellectual Disabilities: Validation of the Self-injury, Aggression and Destruction Screening Questionnaire (SAD-SQ).

Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., Mason, L., & Hatton, C. (2001a). The prevalence of challenging behaviors: a total population study. *Research in Developmental Disabilities, 22,* 77-93.

Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R. *et al.* (2001b). Predicting the persistence of severe self-injurious behaviour. *Research in Developmental Disabilities, 22,* 67-75.

Grey, I., Pollard, J., McClean, B., MacAuley, N., & Hastings, R. (2010). Prevalence of psychiatric diagnoses and challenging behaviors in a community-based population of adults with intellectual disability". *Journal of Mental Health Research in Intellectual Disabilities, 3,* 210-222.

Griffin, J. C., Williams, D. E., Stark, M. T., Altmeyer, B. K., & Mason, M. (1986). Self-injurious behaviour: a state wide prevalence survey of the extent and circumstances. *Applied Research in Mental Retardation, 1,* 105-116.

Guess, D., & Carr, E. (1991). Emergence and maintenance of stereotypy and self-injury. *American Journal on Mental Retardation, 96,* 299-319.

Holden, B., & Gitlesen. (2006). A total population study of challenging behaviour in the county of Hedmark, Norway: prevalence, and risk markers. *Research in Developmental Disabilities, 27,* 456-465.

Hyman, P., Oliver, C., & Hall, S. (2002). Self-injurious behaviour, self-restraint, and compulsive behaviors in Cornelia de Lange Syndrome. *American Journal on Mental Retardation, 107,* 146-154.

Jones, R. S. P. (1999). A 10 year follow up of stereotypic behaviour with 8 participants. *Behavioural Interventions, 14,* 45-54.

Kahng, S., Iwata, B. A., & Lewin, A. B. (2002). Behavioral treatment of self-injury, 1964 to 2000. *American Journal of Mental Retardation, 107,* 212-221.

Kebbon, L., & Windahl, S.-I. (1986). Self-injurious behaviour - results of a nation-wide survey among mentally retarded persons in Sweden. In J. M. Berg & J. M. DeLong (Eds), *Science & Service in Mental Retardation,* 142-148.

Kiernan, C., & Alborz, A. (1996). Persistence and change in challenging and problem behaviours of young adults with intellectual disability living in the family home. *Journal of Applied Research in Intellectual Disabilities, 3,* 181-193.

Kiernan, C., & Qureshi, H. (1993). *Challenging behaviour.* In *C. Kiernan (Ed.). Research to Practice? Implications of Research on Challenging Behaviour of People with Learning Disabilities*, pp. 53-87. Kidderminster: British Institute of Learning Disabilities.

Knapp, M., Comas-Herrera, A., Astin, J., Beecham, J., & Pendaries, C. (2005). Intellectual disability, challenging behaviour and cost in care accommodation: what are the links? *Health and Social Care in the Community, 13*, 297-306.

Konarski, E. A., Sutton, K., & Huffman, A. (1997). Personal characteristics associated with episodes of injury in a residential facility. *American Journal of Mental Retardation*, *102*, 37-44.

Kushlick, A., Blunden, R., & Cox, G. (1973). A method of rating behaviour characteristics for use in large scale surveys of mental handicap. *Psychological Medicine, 3*, 455-478.

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: prevalence and topographies. *Journal of Intellectual Disability Research, 51*, 625-636.

Maisto, C. R., Baumeister, A. A., & Maisto, A. A. (1978). An analysis of variables related to self-injurious behaviour among institutionalised retarded persons. *Journal of Mental Deficiency Research, 22*, 27-36.

McClintock, K., Hall, S., & Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta analytic study. *Journal of Intellectual Disability Research, 47,* 405-416.

McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research, 46,* 239-249.

Murphy, G., Hall, S., Oliver, C., & Kissi-Debra, R. (1999). Identification of early self-injurious behaviour in young children with intellectual disabilities. *Journal of* Intellectual Disability Research, 43, 149-63.

Murphy, G. H., Oliver, C., Corbett, J., Crayton, L., Hales, J., Head, D. *et al.* (1993). Epidemiology of self-injury, characteristics of people with severe self-injury and initial treatment outcome. In C. Kiernan (Ed.), *Research to Practice?: Implications of research on the challenging behaviours of people with learning disabilities* (pp.1-35). Clevedon: British Institute of Learning Disabilities.

Nissen, J. M. J. F., & Haveman, M. J. (1997). Mortality and avoidable death in people with severe self-injurious behaviour: results of a Dutch study. *Journal of Intellectual Disability Research, 41,* 252-7.

Nottestad, J. Aa., & Linaker, O. M. (2002). Predictors for attacks on people after deinstitutionalisation. *Journal of Intellectual Disability Research, 46,* 493-502.

Oliver, C. (1993). Self-injurious behaviour: from response to strategy. In C. Kiernan (Ed.), *Research to Practice? Implications of Research on the Challenging Behaviours of People with Learning Disabilities* (pp. 135-188). Clevedon: British Institute of Learning Disabilities.

Oliver, C. (1995). Annotation: self-injurious behaviour in children with learning disabilities: recent advances in assessment and intervention. *Journal of Child Psychology and Psychiatry, 30,* 909-927.

Oliver, C., McClintock, K., Hall, S., Smith, M., Dagnan, D., & Stenfert-Kroese, B. (2003). Assessing the severity of challenging behaviour: psychometric properties of the challenging behaviour interview. *Journal of Applied Research in Intellectual Disabilities, 16,* 53-61.

Oliver, C., Hall, S., & Murphy, G. (2005). The early development of self-injurious behaviour: evaluating the role of social reinforcement. *Journal of Intellectual Disability Research, 49,* 591-599.

Oliver, C., Petty, J., Ruddick, L., & Bacarese-Hamilton, M. (2012). The association between repetitive, self-injurious and aggressive behavior in children with severe intellectual disability. *Journal of Autism and Developmental Disorders*, 42, 910-919.

Oliver, C., Sloneem, J., Hall, S., & Arron, K. (2009). Self-injurious behaviour in Cornelia de Lange syndrome: 1. Prevalence and phenomenology. *Journal of Intellectual Disability, 53,* 590-603.

Petty, J. (2006). Self-injurious behaviour in children with severe intellectual disabilities. Unpublished PhD thesis, University

Petty, J., & Oliver, C. (2005). Self-injurious behaviour in individuals with intellectual disabilities. *Mental retardation and developmental disorders, 18,* 484-489.

Petty, J., & Oliver, C. Investigating risk-markers for self-injurious and other challenging behaviours in children under the age of five years. *In preparation.*

Richards, C., Oliver, C., Nelson, L., & Moss, J. (2012). Self-injurious behaviour in individuals with autism spectrum disorder and intellectual disability. *Journal of Intellectual Disability Research, 56,* 476-489.

Richman, D. M. (2008). Early intervention and prevention of self-injurious behaviour exhibited by young children with developmental disabilities. *Journal of Intellectual Disability Research, 52,* 3-17.

Richman, D., & Lindauer, S. (2005). Longitudinal functional analysis of stereotypic, proto-injurious, and self-injurious behavior in young children with developmental delays. *American Journal on Mental Retardation, 110,* 439-450.

Robertson, J., Emerson, E., Pinkney, L., Caesar, E., Felce, D., Meek, A. *et al.* (2005). Treatment and management of challenging behaviours in congregate and noncongregate community-based supported accommodation. *Journal of Intellectual Disability Research, 49,* 63-72.

Schmidt, C. O., & Kohlmann, T. (2008). When to use the odds ratio or the relative risk? *International Journal of Public Health, 53,* 165-167.

Sonuga-Barke, E. J. S., (2002). Psychological heterogeneity in AD/HD – a dual pathway model of behaviour and cognition. *Behavioural Brain Research, 130,* 29-36.

Symons, F. J., Sperry, L. A., Dropik, P. L., & Bodfish, J.W. (2005). The early development of stereotypy and self-injury: a review of research methods. *Journal of Intellectual Disability Research, 49,* 144-158.

Taylor, L., Oliver, C., & Murphy, G. (2011). The chronicity of self-injurious behaviour: A long-term follow-up of a total population study. *Journal of Applied Research in Intellectual Disability, 25,* 107-117.

Thompson, C. L., & Reid, A. (2002). Behavioural symptoms among people with severe and profound intellectual disabilities: a 26-year follow up study. *British Journal of Psychiatry, 181,* 67-71.

Turner, M. (1997). Towards an executive dysfunction account of repetitive behaviour in autism. In J. Russell (Ed.), *Autism as an executive disorder* (pp. 57–100). Oxford: Oxford University Press.

Turner, M. (1999). Annotation: repetitive behavior in autism: a review of psychological research. *Journal of Child Psychology and Psychiatry, 40,* 839-849.

Table 1: Relative risk of self-injury, aggression and destruction given gender and severity of intellectual disability across 7 years and under and 8 years and over samples

Child characteristics	Behaviour	Total sample RR (CI)	7 & under RR (CI)	8 & over RR (CI)
Gender	**Aggression**	.74 (.5, 1.11)	.83 (.46, 1.52)	.68 (.4, 1.19)
	Destruction	.81 (.43, 1.51)	.75 (.31, 1.79)	.89 (.36, 2.2)
	Self-injury	.82 (.45, 1.48)	.86 (.37, 1.98)	.77 (.33, 1.8)
	One or more Forms	.78 (.55, 1.1)	.85 (.52, 1.39)	.72 (.45, 1.17)
Severity of intellectual disability	**Aggression**	1.19 (.83, 1.71)	1.35 (.76, 2.39)	1 (.63, 1.6)
	Destruction	.84 (.47, 1.51)	.96 (.41, 2.22)	.78 (.34, 1.78)
	Self-injury	.78 (.44, 1.39)	.81 (.33, 1.98)	.72 (.34, 1.54)
	One or more forms	1.06 (.78, 1.45)	1.1 (.69, 1.77)	1 (.66, 1.51)

CI = 99.9%, * = p < .001

Table 2: Percentage and number of participants for incidence, remission and persistence and no behaviour groups and analysis examining the persistence of self-injury, aggression and destruction between the T1 and T2 studies (left of the bold line). One year incidence and persistence of these behaviours in participants showing them at T1 (right of the bold line).

Behaviour	No behaviour at either stage	Remission	Incidence (Mean = 16.5 months)	Persistence	*P* *(1 tailed)*	Cumulative Incidence over One year (%)	Persistence among participants with behaviour at T1
Aggression	57.04 (235)	9.47 (39)	12.38 (51)	21.12 (87)	<.001	8.25	69.05 (87)
Destruction	70.32 (289)	7.3 (30)	12.65 (52)	9.73 (40)	<.001	8.43	57.14 (40)
Self-injury	76.16 (313)	7.06 (29)	7.06 (29)	9.73 (40)	<.001	4.71	57.97 (40)
One or more forms	46.62 (193)	10.6 (44)	14.49 (60)	28.5 (117)	<.001	9.66	72.67 117

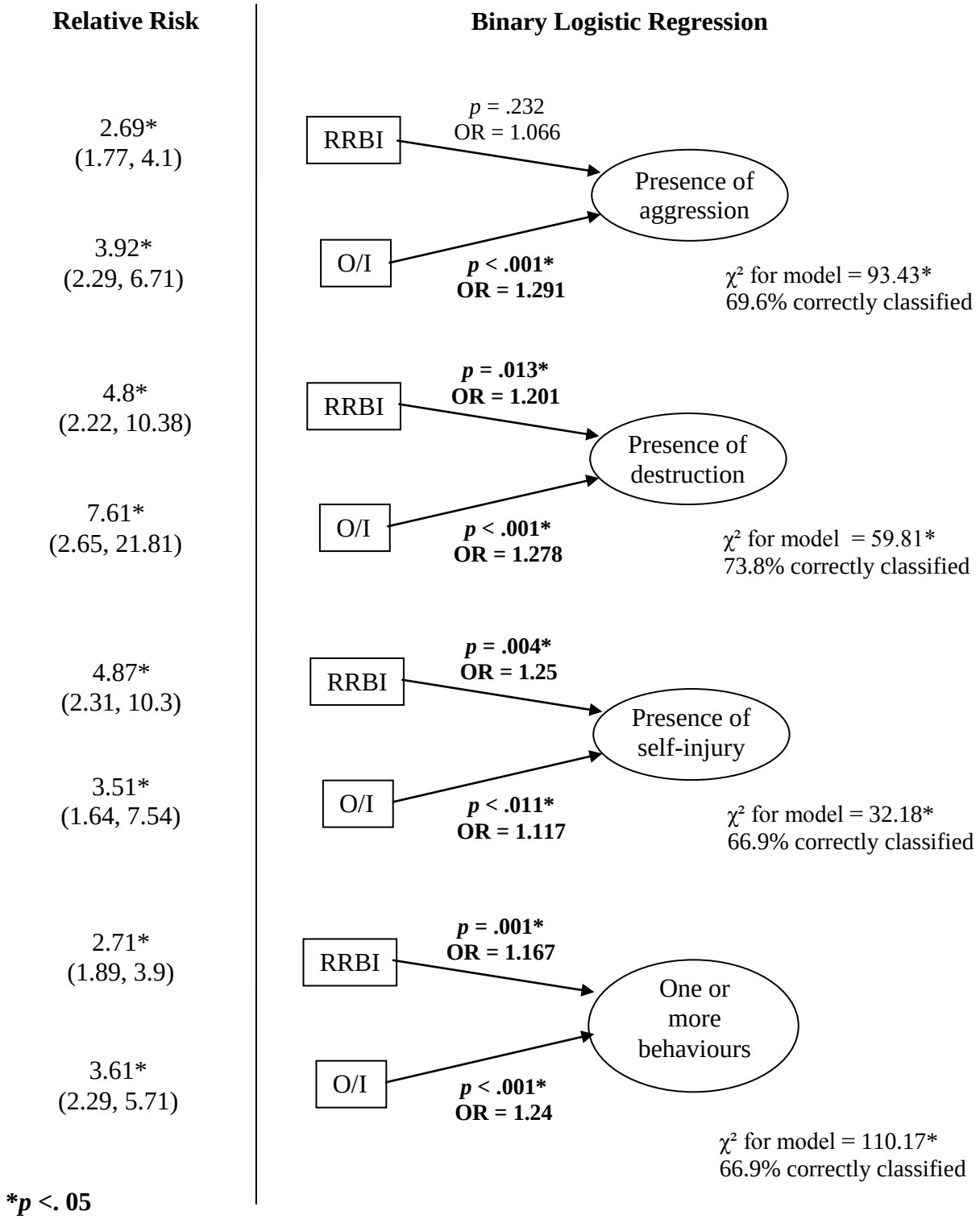
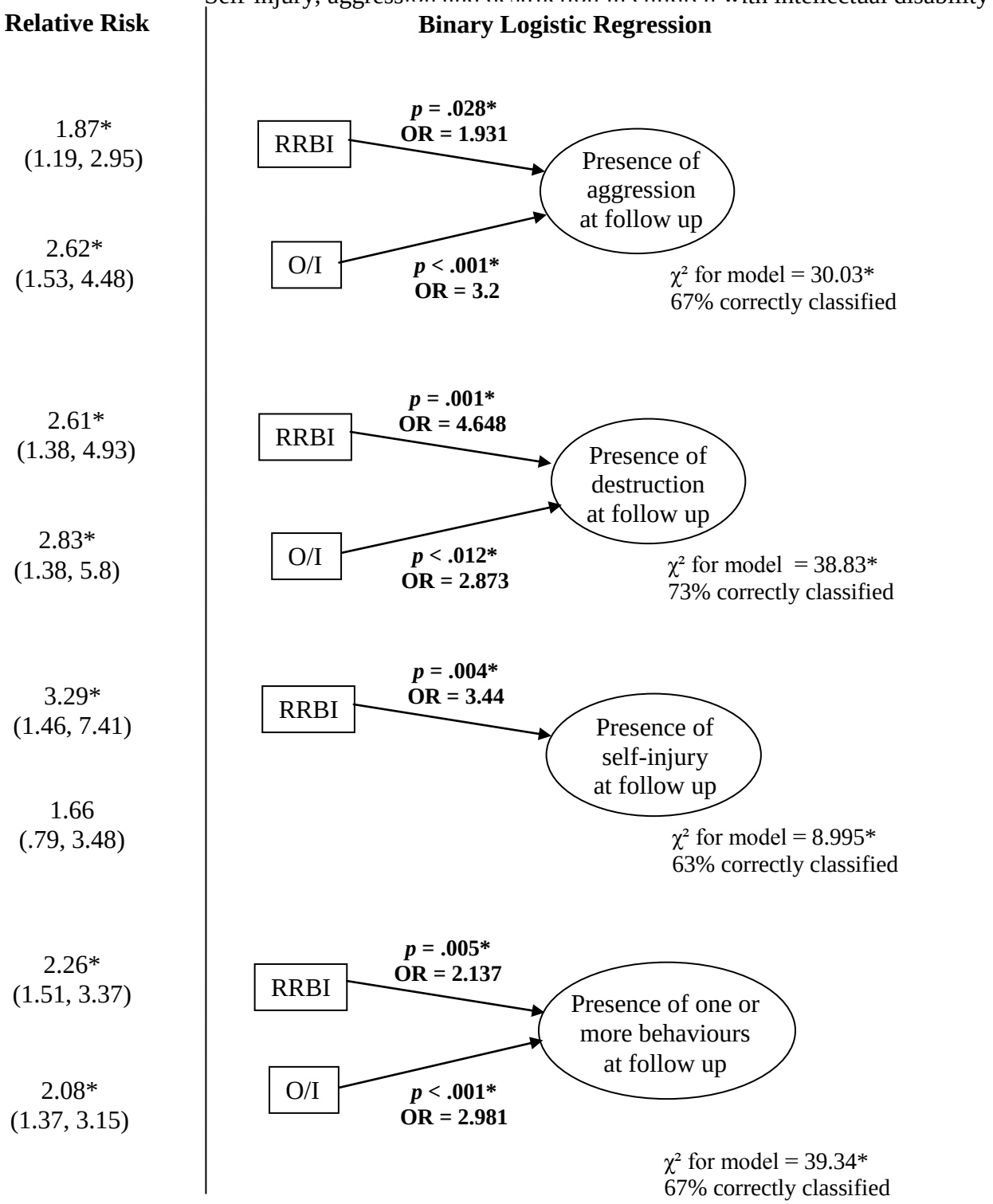


Figure 1: Binary logistic regressions predicting self-injury, aggression and destruction at T1



*** = p < .05**

Figure 2: Binary logistic regression models predicting the presence of self-injury, aggression and destruction at T2

Table 3: Percentage and number of participants with a behavioural correlate at T1 but not T2, T2 but not T1, both T1 and T2 and at neither T1 nor T2 and Cramer's phi analysis examining the persistence of the behavioural correlates between the T1 and 2

Behavioural correlate	T1 - absent T2- absent	T1 - present T2- absent	T1 - absent T2- present	T1 - present T2- present	*p* (1 tailed)
Repetitive and restricted behaviours and interests	34.97 (128)	10.38 (38)	18.03 (66)	36.61 (134)	**<.001**
Overactivity/ Impulsivity	31.88 (110)	17.68 (61)	12.75 (44)	37.68 (130)	**<.001**

Bold = $p < .001$

Table 4: Relative Risk of the Persistence and Incidence of Self-injury, Aggression and Destruction

Behavioural Correlate	Challenging Behaviour	Incidence	Persistence
Repetitive and Restricted Behaviours and Interests	Self-injury	2.66* (1.84, 6.02)	.97 (.42-2.27)
	Aggression	1.34 (.74-1.68)	1.04 (.67-1.61)
	Destruction	2.16* (1.21-2.78)	1.36 (.51-3.65)
	One or more forms	2.49* (1.25, 2.52)	1.09 (.8-1.48)
Overactivity/ Impulsivity	Self-injury	1.11 (.76, 2.34)	.9 (.75-1.58)
	Aggression	2.42 * (1.36-3.13)	1.14 (.64-2.01)
	Destruction	2.07* (1.2-2.86)	1.2 (.32-4.43)
	One or more forms	2 (.99-1.99)	1.02 (.69-1.51)

CI = 99.9%, * significant